Office of Administration

Missouri Head Injury Advisory Council

FY 88 ANNUAL REPORT and ACTION PLAN UPDATE

STATE OF MISSOURI
OFFICE OF ADMINISTRATION
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Office of Administration

Missouri Head Injury Advisory Council

FY 88
ANNUAL REPORT

and

ACTION PLAN
UPDATE

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OFFICE OF ADMINISTRATION

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November 15, 1988

The Honorable John Ashcroft
Office of the Governor
State Capitol Building, Room 216
Jefferson City, Missouri 65101

Dear Governor Ashcroft:

I respectfully submit to you the Missouri Head Injury Advisory Council Annual Report summarizing activities of the council for the period of July 1, 1987, through June 30, 1988. Since its creation in 1985, the council has been laying the foundation for building a service delivery system in this state for survivors of head injury and their families. Two years ago the council initiated legislation, which passed, establishing a statewide reporting system to accurately document head and spinal cord injuries so that we can determine incidence and prevalence of head injuries in this state. The registry, which was implemented July 1, 1987, also provides valuable information relating to cause of injury, to the emergency medical service delivery system, the disability level as a result of the injury, costs associated with injury, and the need for rehabilitation and long term care following hospitalization. The council is currently defining a service delivery system in Missouri utilizing the registry data and other sources.

As chairman of the council representing a parent of a son with a head injury, I would be remiss, however, if I did not bring to your attention the unmet needs of survivors of traumatic head injury. Many could be removed from the disability subsidy rolls if they were given the opportunity and training for sheltered, supported or competitive employment. Appropriate rehabilitation and community support may allow many to reside independently, semi-independently or with families, thus avoiding costly institutionalization. Others with acute medical needs may be better served and rehabilitated in well trained and funded nursing facilities as opposed to more expensive acute hospital settings.

With your continued support and the support of the Missouri General Assembly, the council believes that together we can address many of these unmet needs by implementing a full continuum of services, including prevention, designed to re-integrate persons with head injury into the community. We welcome the opportunity to discuss the course of direction we should take and your guidance along the way.

Sincerely,

Judith A. Ferguson

Judith A. Ferguson
Chairman

Preface

Head injury is the leading cause of death and disability from birth to the age of 44 killing more than 140,000 Americans each year and severely disabling another 50,000 to 70,000 persons intellectually, physically and psychologically. The majority of injuries occur to males between the ages of 15 to 25. Fifty percent of all head injuries are caused by motor vehicle accidents with falls, diving accidents, industrial accidents, assaults and recreational accidents causing the rest of the injuries.

The Missouri Head Injury Advisory Council was created in 1985 to study the unique needs of survivors of head injury and their families including prevention, rehabilitation and community support programs. The council, established under Section 192.745 RSMo and assigned to the Missouri Office of Administration, is (1) to make recommendations to the governor for developing and administering a state plan to provide services for Missourians with head injury and (2) to report annually to the commissioner of administration, the governor and the general assembly on its activities, results of its studies and the recommendations of the council. The members of the council represent the Missouri General Assembly, consumers, family members, professionals, and state agencies administering such programs as special education, vocational rehabilitation, mental health, health, public safety, medical services, and vocational education.

In keeping with the mandate, this report is organized into two major chapters: (1) *Description of Service Model & Needs* and (2) *Action Plan Update.* In Chapter One, an attempt is made to describe existing services. The inclusion of known providers should not be interpreted as an endorsement of those particular services, but as an attempt to describe the current service delivery system. It is also possible that services are being provided by other agencies which the council is unaware of and, thus, not included in that section.

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Missouri Head Injury Advisory Council

ANNUAL REPORT and *ACTION PLAN UPDATE*

Introduction

Referred to as the "silent epidemic", head injury is the leading cause of death and disability up to the age of 44. Fifty percent of all head injuries are caused by motor vehicle accidents. Falls, diving accidents, industrial accidents, assaults, weapons, and recreational accidents cause the remaining 50 percent. The majority of the victims of head injury are males between the ages of 15 to 25.

Emergency medical and technologic advances have resulted in greater survival rates for persons who have sustained a traumatic head injury. The number of survivors will continue to increase as emergency medical services and hospital care, including trauma centers, continue to improve and become more readily available. The increased number of survivors has placed greater demands for rehabilitation services, long term care, supervised residential living, vocational rehabilitation, supported employment, and community support programs. Many of these services are available to other disability populations, however, the services are either difficult to access or not readily available to persons with head injuries.

Creation of Council

During the summer of 1984, a Joint Interim Committee on Head Injury established by the Missouri General Assembly held several hearings around the state. The committee made several recommendations including the creation of an advisory council to continue studying the needs of persons with head injury and their families and to formulate recommendations to meet those needs. The Missouri Head Injury Advisory Council was subsequently established under an Executive Order March 5, 1985, by Governor John Ashcroft, who also appointed 21 of the 25 members. The other four members represent the Missouri General Assembly. Two members of the council are state senators appointed by the Senate President Pro Tempore and two are state representatives appointed by the Speaker of the House of Representatives. The remaining members represent parents, consumers, professional, and various state agencies representing education, mental health, health, public safety, medical services, vocational rehabilitation, and vocational education. The council was administratively assigned to the Missouri Office of Administration, Division of General Services.

Legislative Authority

In 1986, legislation was enacted which established a head and spinal cord injury registry and established the Missouri Head Injury Advisory Council statutorily. The council is to make recommendations to the governor for developing and administering a state plan to provide services for Missourians with head injury. The council is to be advisory and shall:

(1) Promote meetings and programs for the discussion of reducing the debilitating effects of head injuries and disseminate information in cooperation with any other department, agency or entity on the prevention, evaluation, care, treatment and rehabilitation of persons affected by head injuries;

(2) Study and review current prevention, evaluation, care, treatment and rehabilitation technologies and recommend appropriate preparation, training, retraining and distribution of manpower and resources in the provision of services to head injured persons through private and public residential facilities, day programs and other specialized services;

(3) Recommend what specific methods, means and procedures should be adopted to improve and upgrade the state's service delivery system for head injured citizens of this state;

(4) Participate in developing and disseminating criteria and standards which may be required for future funding or licensing of facilities, day programs and other specialized services for head injured persons in this state; and

(5) Report annually to the commissioner of administration, the governor, and the general assembly on its activities, and on the results of its studies and the recommendations of the council.

This report provides an update of the council's progress in meeting its goals and objectives of which have been defined to meet the major goal of recommending a statewide service delivery system for survivors of head injury and their families.

Definition of Head Injury

"Head injury" or "traumatic head injury" is defined as: "a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease of one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms and congenital deficits are specifically excluded from this definition" (Section 192.735 RSMo).

Head injury or brain injury is a traumatic insult to the brain requiring extensive services over an extended period of time. Although the injury is not always visible, it may cause physical, emotional, intellectual, social and vocational changes. There are two types of head injury: closed head injury and open head injury. A "closed head injury" refers to damage that occurs within the skull after a blow to the head. Although the skull may stop on impact, the brain will often continue to whip back and forth against the skull from within causing damage. The second category of head injury referred to as "open head injury" is a visible assault and may be the result of a gun shot wound or an accident.

The symptoms of head injury may vary greatly, depending on the extent and location of the injury. The following are three types of impairments associated with head injury. Any or all of the impairments may occur in varying degrees and there may be other symptoms than those listed below:

- *Physical impairments*; including speech, vision, hearing and other sensory impairments; headaches, lack of coordination; spasticity of muscles, paralysis of one or both sides and seizure disorders. Although many survivors of head injury may appear to be recovered physically, they may still have problems with visual perception or fine motor control.

- *Cognitive impairments*; which may result in memory deficits, either long or short term; and problems with concentration, attention, perception, communication, reading, writing, planning, sequencing or judgment. Learning problems which have been identified include decreased ability for abstraction less initiative and distractibility.

- *Psycho-Social-Behavior-Emotional impairments*; including fatigue, mood swings, denial, self-centered, anxiety, depression, lowered esteem, sexual dysfunction, restlessness, lack of motivation, inability to self-monitor, difficulty with emotional control, inability to cope, agitation, excessive laughing or crying or difficulty relating to others. Personality can be altered and the person may become argumentative or become socially withdrawn and unable to interact with peers. Often a person with a head injury will insist he or she can understand completely when in actuality is totally confused.

Incidence/Prevalence

The National Head Injury Foundation (NHIF) and the Missouri Head Injury Association have estimated that 10,000 Missourians will annually suffer from a head injury. Of that number...

... 1,000 will be severely permanently disabled physically, intellectually and emotionally.
... 4,000 will be moderately disabled.
... 5,000 will be mildly injured.

The Missouri Department of Health implemented the head and spinal cord registry July 1, 1987, requiring hospitals to report head injuries as mandated by law. The department will compile the data gathered between January 1, 1988, and January 1, 1989, making data available regarding the incidence of head injury. The department is projecting the hospital to report 10,000 injuries during the reporting period. One it's long range goals is to use the data to determine the prevalence of head injury.

Base on approximately 3,300 reports, the Department of Health has described the following as a profile of the head/spinal cord injured patient in Missouri:

- Male
- Age 15-24
- Motor Vehicle Accident
- Transported by Ground Ambulance
- Intracranial Injury Without Spinal Fracture
- 3.3 Hours in Emergency Department
- Emergency Department Disposition to Floor
- Stays in Hospital 6.2 Days

Chapter One:

DESCRIPTION of SERVICE MODEL & NEEDS

Array Of Services

The course of rehabilitation will vary according to the patient's needs and the availability of services. Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury needs can range from full time care to community re-integration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care. Thus, services must be flexible, but also allow for the most frequent progressions. Rehabilitation of persons who have sustained traumatic head injury is based upon small steps emphasizing increased demands until the person's maximum level of independence is established. While returning to the community living is the ultimate goal, however, it must be recognized that the level of functioning will vary and survivors of head injury may require differing support services.

No state to date has developed a comprehensive statewide service delivery system addressing all of the service components for persons with head injuries. The Missouri Head Injury Advisory Council has defined services which are organized into categories similar to both the medical/health care community and the mental retardation/ developmental disabilities community. Major service areas in the delivery system include: Prevention; emergency medical and medical care; rehabilitation; case management; residential; and community support services such as therapies, counseling, respite, social and leisure activities.

Some of these services are in place and are provided by state and local agencies. Some of the services needed (i.e. case management, residential, supported employment) are available to other disability groups, but are not available specifically to persons with a head injury.

Description of Service Model

Prevention

The incidence and severity of head injury can be reduced through prevention and early intervention activities. Motor vehicle accidents account for 50 percent of all head injuries. Falls, diving accidents, industrial accidents, assaults, weapons and recreational accidents together cause the remaining 50 percent.

Injury has traditionally been regarded primarily as an unavoidable accident rather than a health problem. However, injuries can be prevented with a variety of strategies. Three general strategies are available to prevent injuries: (1) **Persuade** persons at risk to alter their behavior, (2) **require** individual behavior change by law or administrative rule and (3) **provide** automatic protection by product and environment design.

In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma injury by the National Academy of Sciences. The committee issued the report *Injury in America: A Continuing Health Problem* in 1985. One of the findings of the committee was the lack of the data necessary to allow for the study of the epidemiology of most injuries. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

Emergency Medical & Medical Services

The outcome of injury depends not only on its severity, but also on the speed and appropriateness of treatment. Rehabilitation should first begin with the emergency medical services team at the scene of the accident. Proper attention should be provided in order to prevent further injury. Trained paramedics are able to attend to airways, treat shock, and monitor a patient's condition. They can also notify the receiving hospital regarding the patient's condition and the estimated time of arrival.

The emergency medical services system has improved over the years. Much of the improvements have been attributed to the military which has used

triage methods at the scene of the accident and helicopters to transport severely injured patients to receive care in a minimum amount of time during military conflicts. "Communication systems are needed to facilitate decision making, injury management at the site, and the rapid delivery of the patient to a hospital that can provide the needed care," according to the report, *Injury in America: A Continuing Health Problem.*

After the victim is attended to at the site of the accident, he or she is usually, then, transported to the hospital emergency department where the medical team tries to stabilize the patient as well as to diagnose the immediate problems. For more than a decade the American College of Surgeons has pushed for a regional system of hospital-based trauma centers. A trauma center is a hospital where the medical staff has made a commitment to provide 24-hour "in-house" coverage by surgeons, anethesiologist and supporting staff to care for trauma patients.

Many patients with "minor" head injury may be discharged from the emergency department. (Such patients, however, later may experience problems such as headaches, memory disturbances, confusion and disorientation.) For others who may be more severely injured, surgery may be performed for various reasons. After surge y, he may be moved to the intensive care unit for acute care until he no longer needs acute monitoring.

If the patient is comatose, he or she may be provided stimulation and physical therapy to prevent deformity or atrophy of the muscles and bones. If the patient appears to be in a persistent vegetative state, or emerging from coma, the hospital may discharge the patient to a nursing facility.

Rehabilitation

Rehabilitation refers to a comprehensive series of interventions for physical, medical, cognitive, psychological disabilities designed to restore a person to his or her maximum functional potential. This process should begin immediately after the injury as possible. Some general hospitals maintain a rehabilitation unit where physical, speech and occupational therapies are provided. As the patient progresses medically, he may receive such therapies and may be moved to a rehabilitation unit or a separate short-term rehabilitation hospital which, in addition, may also provide cognitive rehabilitation.

The patient may be evaluated by a team of professionals, including a neuropsychologist or psychologist, which, then, develops a rehabilitation program to address the patient's problems. These problems may be related to memory, attention, movement, balance, personality changes, difficulty with complex thinking and with judgment, inappropriate behavior, and difficulty with speech and language. Patients are usually discharged after reaching a plateau of recovery, although many may still require continued rehabilitation beyond the acute stage.

The Missouri Head Injury Advisory Council has defined three types of rehabilitation programs: (1) **Acute Brain Injury Rehabilitation**, (2) **Functional Living Rehabilitation**, and (3) **Transitional Living Rehabilitation**. Most often, after traumatic head injury, the patient goes from acute medical care to ***acute rehabilitation*** which focuses on physical and gross cognitive deficits. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive and behavioral functioning. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Functional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. Emphasis in this program is on functional cognitive, memory, or perceptual deficits, and appropriate interpersonal skills. Services may be delivered on an inpatient (residential) or outpatient (day program) basis.

Transitional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have sustained traumatic brain injury and who have completed acute and functional living rehabilitation programs or who have no significant need for such services prior to transitional living programs. In these programs, participants would typically move from close observation and supervision to independent living with minimal supervision. Transitional living programs may exist independently or may be part of a larger program. The program should provide safe, accessible housing which allows transition from group living situations to independent living. Housing facilities should include provision for 24-hour supervision.

The goal of rehabilitation is to enable a survivor of head injury to return to his/her employment/school and to his or her home environment. Many will return

to work provided that certain modifications in the work environment take place which will enable the person to return to his or her job. Others will require extensive rehabilitation or programs which specialize in pre-vocational or vocational rehabilitation in order to be able to engage in competitive employment. For those who will not be able to engage in competitive employment without some type of assistance, other alternatives will need to be available.

Pre-vocational/Pre-employment Training readies a person for vocational rehabilitation. The program addresses behavioral and/or cognitive compensation strategies learned through cognitive rehabilitation and/or work adjustment training. This type of program often fills a gap between functional/transitional rehabilitation and vocational rehabilitation services provided by the Missouri Division of Vocational Rehabilitation.

Vocational Rehabilitation readies a person for employment. The federal Rehabilitation Act of 1975 as amended is administered through the Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. Vocational Rehabilitation is a program designed to help physically or mentally disabled persons become employable. Many services are provided under the federal program of which some are free and others assessed by the ability to pay. Some of the services made available to clients are as follows:

1.) A doctor's examination to assess the severity of the disability.
2.) Medical and hospital care to reduce the disability and improve changes for employment.
3.) The purchase of such items as artificial arms and legs, braces, wheelchairs or hearing aids to increase the ability to work.
4.) Job training, which may include college education, commercial or trade school, or on-the-job training.
5.) Work evaluation and adjustment.
6.) Transportation allowance while receiving medical treatment or job training arranged by the vocational rehabilitation counselor.
7.) An allowance sufficient for noon meals if job training is provided in the client's home community.
8.) The cost of room and board if job training is provided in the client's home community.
9.) Equipment needed for employment.
10.) Help in finding a job.
11.) Help in solving problems encountered on the job.

To be eligible for services through the Division of Vocational Rehabilitation a person must meet the following requirements:

1.) The presence of a physical or mental disability which for the individual constitutes or results in a substantial handicap to employment and
2.) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability.

Employment

Supported Employment refers to competitive employment occuring in integrated work settings and being performed by individuals with handicaps for whom either competitive employment has traditionally occurred or competitive employment has been interrupted or become intermittent as the result of a severe disability and which, because of their handicaps, need ongoing job coaching, psychosocial and other support services to perform such work.

Sheltered Workshop Employment refers to an occupation-oriented facility operated by a not-for-profit corporation, which, except for its staff, employs only persons with a handicap and has a minimum enrollment of at least fifteen employable handicapped persons (Section 178.900 RSMo.). To be eligible persons must be certified by the Division of Vocational Rehabilitation .

Day Programs maintain the intellectual, emotional, social, vocational, and physical capacity of a person who may have received services from an acute rehabilitation, functional living rehabilitation and/or transitional living program, and is unable to maintain a job or participate in a vocational or educational program.

Residential Services

Ideally, a person suffering from a head injury would return to his/her natural environment following medical and rehabilitation care whether that be to live with a spouse, other family member(s) or independently/ semi-independently. For those who are unable to return to his/her natural environment independently, then some type of housing or support which provides supervision and protection may be nee
ded. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting.

Home health care agencies provide three type of services: (1.) In-home vists by nurses, which generally are covered by Medicaid or Medicare; (2) homemaker program providing non-medical assis-

tance, such as grocery shopping, to elderly or handicapped persons who would otherwise be in nursing homes, which is a Medicaid service; and private duty (8 hours at a time), which is generally covered by private pay, insurance and sometimes Medicaid.

Personal Care Assistance provides in home assistance which may include help with dressing, bathing, eating or other personal care activities, thus enabling a person to reside in a semi-independent living situation.

Independent Living Centers may provide counseling and /or supervision on a periodic basis, thus assisting the person with head injury to live semi-independently.

Supervised Living Arrangement is a place of residence that substitutes for the individual's own home or for the home of the individual's family. It should provide environments that are conducive to the development of adaptive behavior, self help and independent living skills. The residence also should facilitate, to the greatest possible extent, continuity with culturally normative living patterns. It should be located within the community and should include both generic and specialized services.

Structured Residential Placement provides 24-hour care and treatment for those individuals who manifest severe behavior problems. The setting may exist independently or as a part of a larger program.

Coma Management Programs may accept such individuals once they are medically stable and attempt to achieve improvement by the use of various stimulus techniques. Skilled nursing care and physical therapy are important elements of these programs.

Respite Care provides temporary relief to the family, thus enabling the family to care for the person in his or her home.

Community Support Services

Community support services provide ongoing or intermittent support to survivors of head injury and their families following rehabilitation, thus, enabling them to live in the community on their own or with family or other assistance. These services may exist independently or be part of a larger program. Such services provide ongoing or intermittent support in several areas including recreation, counseling, transportation, therapies, and other support services. Case management has been categorized as a support service. As in other fields, case management is viewed by the Missouri Head Injury Advisory Council as playing a major role in the provision of services and should be addressed as a major component of the service delivery system.

Counseling is an individual or a family intervention to provide psychological support, direction, or change with regard to feelings or thoughts elicited or resulting from brain injury.

Family Training is a program of training for family members which provides skills to assist the person with a head injury in the family and outside of the home, emphasizing a program of structural activities. In essence, family members are trained to become their own service provider.

Transportation refers to the provision of necessary travel accomodations for persons with brain injury to and from places where they are employed or where they receive other services. Transportation may include the provision of driver's education, adaptive automobile devices, and/or training in the use of public transportation systems.

Recreation/Socialization activities may be provided in specialized programs specifically for persons with head injury or in existing community programs.

Case Management & Program Planning

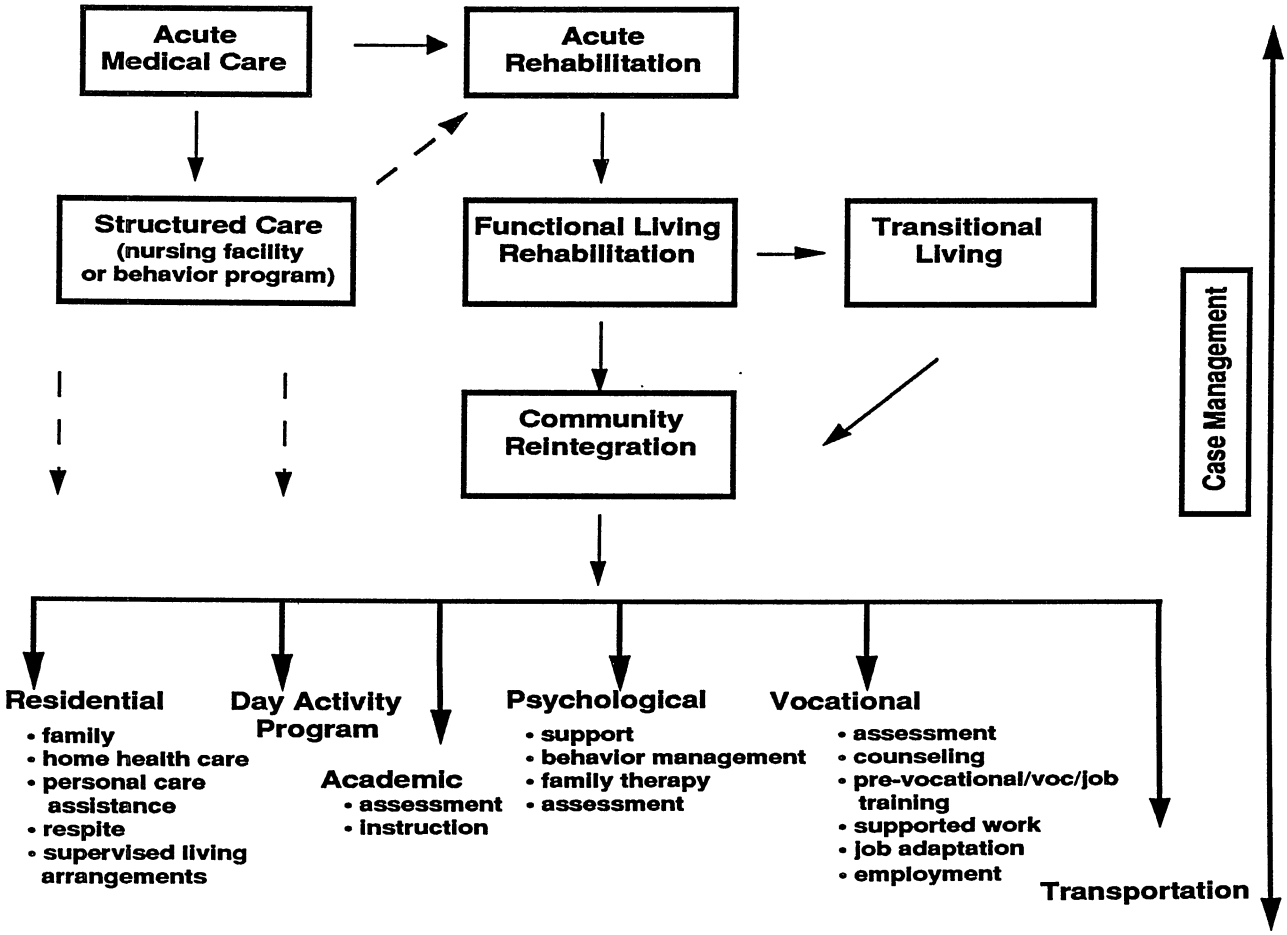
Case management is an encompassing process which is the link between the client and the service delivery system. It is a method that analyzes client needs and assesses area resources in order to provide, procure, purchase, and coordinate services for persons with a brain injury. The process must be flexible to allow for the reformulation of service plans relative to changing client needs. It allows clients to remain in their least restrictive environment and fosters the concept of normalization. Case management generally consists of the following functions: (1) Intake; (2) service planning (developing an individualized rehabilitation plan); (3) service coordination; (4) service monitoring/quality assurance; (5) supportive counseling; and, (6) client advocacy.

Evaluation/Assessment services consist of the initial clinical interview for (1) determining the level of cognitive, speech/communication, independent living skills, emotional, physical and/or vocational functioning; (2) determining the need for rehabilitation or specialized service(s); (3) and/or development of a rehabilitation plan. An interdisciplinary team should provide the initial or ongoing assessment and develop treatment/rehabilitation plans based upon the assessment. Initial or ongoing assessment should address the following:

- Medical and neurological issues
- Health and nutrition
- Sensorimotor capacity including gross and fine motor strength and control,sensation, balance, joint range of motion, mobility and function
- Cognitive capacity
- Perceptual capacity
- Communicative capacity
- Affect and mood
- Interpersonal and social skills
- Behavior
- Activities of daily living including self-care, home and community skills
- Recreation and leisure time skills
- Educational and/or vocational capacities
- Sexuality
- Family
- Legal competency of the person
- Community reintegration, including appropriate post-discharge services
- Environmental modification
- Adjustment to disability

Program Evaluation/Standards/Certification are the measures against which a program organization or agency is compared to monitor and assess its common practices, quality, and effectiveness in carrying out program and client goals and objectives.

Missouri Head Injury Advisory Council
Service Delivery System
for Missourians with Head Injury



The Current Service System

Prevention

Head Injury Registry

The Missouri Department of Health implemented the head and spinal cord injury registry July 1, 1987, as the result of legislation which passed during the 1986 legislative session requiring all hospitals to report all head and spinal cord injuries to the department. The department is to, in turn, report at least annually data regarding head injuries to the Missouri Head Injury Advisory Council. Once that information becomes available, Missouri will be in a position to study and address the extent of injury in Missouri and the effectiveness of laws and educational programs directed toward the prevention of injuries. (The registry data will also allow the state to assess emergency medical services and hospital care and treatment as well as the extent of injuries and the resulting disabilities.)

Missouri is unique in that the state has five data systems which other states do not have: Missouri Head and Spinal Cord Injury Registry, Statewide Trafficway Accident Reporting System (STARS), Missouri Ambulance Reporting System (MARS), Hospital Admissions System, and the Death Certificates System. Four of these systems are administered by the Department of Health. The fifth system, STARS, is administered by the Missouri State Highway Patrol.

These systems could be linked which would allow the state to have a comprehensive data system to study causes of injury, costs of injuries, and so forth. Both the Missouri Department of Public Safety, Division of Highway Safety, and the Department of Health, as well as the council, have been pursuing funding to link the systems.

State Laws

Missouri has several laws designed to reduce fatalities and injuries including: mandatory seat belt law for occupants in the front seat of automobiles, child safety restraint for children under the age of four, motorcycle helmet usage law for all riders,and severe penalties for DWI (Drinking While Intoxicated). In addition, Missouri has passed legislation requiring all ATV (all terrain vehicle) drivers under the age of 18 to wear a helmet and persons under the age of 16 must be supervised by an adult.

Public Education

The Missouri Head and Spinal Cord Injury Prevention Project, University of Missouri-Columbia, conducts school assemblies addressing the need for exercising good judgment in order to avoid unnecessary accidents. The Project assisted in the making a nationally acclaimed, award winning film called *Harm's Way* featuring young adults from Missouri with head and spinal cord injuries. The prevention program has been modeled in various parts of the state, as well as nationally. The Council has supported expanding the program statewide and has supported the program in its efforts to evaluate the effectiveness of the program. The program receives financial assistance from the Missouri Department of Health, Missouri Division of Highway Safety, the Missouri Safety Belt Coalition and other sources.

Other educational efforts regarding safety are conducted statewide and locally by or with support from the Missouri State Highway Patrol, the Missouri Safety Belt Coalition, Missouri Safety Council, and the Missouri Division of Highway Safety.

Emergency Medical & Medical Services

Trauma Center System

Until legislation passed during the 1987 session, Missouri's trauma center system was voluntary on the part of the hospitals. The Missouri Department of Health developed Trauma Triage Protocol to assist emergency department personnel in the treatment of trauma patients. Like the trauma center program, this protocol was voluntary. The legislation which establishes a trauma center system requires the department to develop criteria for a trauma center and to designate trauma centers after on site review. The legislation also requires licensure of air ambulances and requires all ambulances to transport seriously injured patients to the closest designated trauma center or hospital according to protocol developed by the department. The legislation established the State Emergency Medical Services Council statutorily which is to assist the department with developing rules and regulations necessary to implement the new requirements and to continue to develop recommendations for improving the emergency medical services system.

The Department of Health, Division of Health Resources, through its Bureau of Emergency Medical Services administers the State Ambulance Licensure Law. Its programs includes: (1) Review and approval of curricula at training facilities that offer courses for emergency medical technicians (EMT), mobile emergency medical technicians (MEMT), emergency medical technician paramedics (EMT-P), first responder and corresponding refreshers courses; (2) develop and administer uniform EMT and MEMT certification tests; and (3) develop and coordinate a statewide EMS communications systems.

The statewide emergency medical communications systems includes 141 hospitals with two-way radio capabilities for communicating with ambulances. This system enables an ambulance attendant to radio a hospital to receive advice from a physician or other emergency department personnel concerning care of an emergency patient that the ambulance transporting.

The head and spinal cord injury registry data not only collects data with regard to the number of injuries, but also with regard to method of transportation, length of time in the emergency department, medical treatment provided, disposition of the patient and so forth. Through data collected from the registry, the Department of Health is able to provide hospitals a report listing specific cases identified by audit filters that hospital quality assurance committees may want to review and to take action in order to remediate any potential problem in the emergency and medical care service delivery system.

Rehabilitation Services

Acute, Functional and Transitional Rehabilitation

Rehabilitation programs for survivors of head injury are relatively new. Most of the programs providing services are private facilities. Several hospitals provide acute rehabilitation and outpatient rehabilitation services such as speech therapy, physical therapy and occupational therapy on a limited basis. A few hospitals and rehabilitation facilities provide functional living rehabilitation services. Most of the programs require the patient or client to have the ability to pay for services or have access to third party pay such as insurance or worker's compensation. For those who do not have the ability to pay, the financial resources are limited. The Missouri Medicaid program provides very little reimbursement for outpatient therapy services. However, legislation passed during the 1988, session which not only expands Medicaid eligibility for children, also expands services to include comprehensive day rehabilitation, defined as post acute (functional living) rehabilitation for trauma patients.

As the result of legislation passed during the 1985 session, the name of the State Chest Hospital was changed to the Missouri Rehabilitation Center. The facility, administered by the Missouri Department of Health, is located in Mt. Vernon. A head injury unit was established January 1986 from a state appropriation designated for that purpose. The Missouri Rehabilitation Center provides acute rehabilitation, functional living (residential) and transitional rehabilitation programs.

Also during the 1985 session, an appropriation ($500,000) was made to the Department of Health for purposes of purchasing services for survivors of head injury. The department administered the program for two years. The program (reduced to $314,685 for FY'88-89) was transferred to the Office of Administration, Division of General Services, July 1, 1987. From the appropriation the Office of Administration extended contracts to Rusk Rehabilitation Center, Columbia, and Truman Medical Center-East for functional rehabilitation services. Both programs provide services on an outpatient basis. Rusk Rehabilitation Center through its Brain Injury Rehabilitation Program serves eight clients on a daily basis and the Transitional Learning Center, Truman Medical Center-East serves nine clients on a daily basis.

Private programs which provide functional living rehabilitation services include Rebound, Inc., a health care corporation, located in Lee's Summit, and Neurorehabilitation Centers of St. Louis, subsidiary of HEALTHSOUTH Rehabilitation, a publicly-traded corporation. Both of these programs offer other types of services for persons with head injury. SSM Rehabilitation Institute, a not-for-profit rehabilitation facility operating facilities in St. Louis and St. Charles, also offers functional living rehabilitation services. Irene Walter Johnson operated by the Washington University Medical Center opened the Head Injury Resource Center in March 1986 offering functional living rehabilitation services as well as prevocational training and job placement. The services are offered in an outpatient setting.

Rebound, Inc., broke ground in the spring of 1988 to

construct a 40 bed transitional living center. The transitional program is designed for the higher functioning individual in preparation for community reentry. Rebound accepts clients with the ability to pay or who have access to third party pay such as insurance or worker's compensation.

Pre-Vocational & Vocational Rehabilitation

The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injury. The division provides on going in-service training regarding head injury to its counselors to assist them in securing appropriate vocational services. The division purchases services for its clients from vendors rather than providing direct services.

The first vocational rehabilitation program recognized as expanding its services to head injured clients is Metropolitan Employment Services, St. Louis, with assistance from the division. The division also obtains vocational training services for clients with head injury from the following agencies: Advent Enterprises, Columbia; Goodwill Industries, St.Louis; Life Skills Foundation, St. Louis; and Rehabilitation Institute, Kansas City.

Through a cooperative effort involving Truman Medical Center-East and Rehabilitation Institute, both of Kansas City, and the Division of Vocational Rehabilitation, a job training program was developed for persons with head injury in the Kansas City area. Graduates of the Transitional Learning Center, Truman Medical Center-East, and other potential candidates for the job training program referred to the division for job placement are evaluated by the Rehabilitation Institute. Those eligible are placed in temporary hospital jobs at Truman Medical Center. Job coaches are provided by Rehabilitation Institute with funding from the division. Job performance is monitored by the Transitional Learning Center staff. Duration of the temporary positions range from three to six months and the trainees receive wages.

Supported Work

The Missouri Division of Vocational Rehabilitation receives federal funding for time limited supported work programs. One of the requirements is a demonstration that long term support is available to assist the person in maintaining employment before federal dollars can be used. Supported work programs have developed in Missouri for persons with developmental disabilities or mental illness as the Missouri Department of Mental Health and local mill tax boards are able to make some commitment for long term support. However, supported work funding has not been available to persons with head injury due to the lack of assurance for long term support.

Advent Enterprises, Inc., a not-for-profit corporation in Columbia offers a pre-vocational/employment training and is under contract with the Office of Administration, Division of General Services to provide services to approximately six persons at one given time. Blue Valley Head Injury Center, a not-for-profit organization, opened a program during the summer of 1988 designed to provide a sheltered workshop environment to assist clients to learn the work skills necessary to re-enter the community workforce. In the event community employment is not possible due to the severity of the client's deficits, the person can continue to work in the sheltered workshop environment. The program charges for services.

It is not certified by the Missouri Department of Elementary and Secondary Education, Division of Special Education, as a sheltered workshop eligible for state sheltered workshop subsidy. The division does not allow sheltered workshops to be established for one specific disability group as the division interprets the state law establishing sheltered workshops as serving all handicapped persons eligible for sheltered employment.

A day program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association with funding from the head injury state appropriation, presently being administered by the Missouri Office of Administration, Division of General Services, in FY'86. The program provides a variety of day program activities to ten persons three days a week.

Education

The Missouri Department of Elementary and Secondary Education, Division of Special Education, has assigned staff to assist school districts with the provision of educational services to students with head injury. The division has prepared a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury*, outlining educational responsibilities to be used in conjunction with the manual developed by the National Head Injury Foundation.

Residential Services

Personal Care Assistance/Independent Living Centers/Home Health Care

There are five independent living centers throughout the state which provide in varying degrees personal care, in-home care and other independent living services to persons with disabilities. Some of the centers do offer their services to persons with head injury. State funding is appropriated to the Missouri Division of Vocational Rehabilitation for personal care attendant services. The independent living centers administer these funds at the local level. Services have been limited due to the appropriation.

Opportunities Unlimited, an independent living program in Columbia, is under contract with the Missouri Office of Administration, Division of General Services, to provide in-home, counseling and other supervision for those living independently/semi-independently. Some of the home health care agencies also provide in-home care (medical) and homemaker services for persons needing such care in the community.

Supervised Residential Programs

Supervised residential programs (apartment living or group homes) providing long term housing have yet to be developed for survivors of head injury in Missouri. Persons requiring long term care or specialized care have generally sought services from the Missouri Department of Mental Health through its Division of Comprehensive Psychiatric Services and Division of Mental Retardation and Developmental Disabilities and from nursing homes. Some have sought services outside of Missouri. Interest has been expressed in developing supervised living arrangements for persons with head injury, but funding has yet to be secured for this type of service.

The Neurorehabilitation Centers of St. Louis is planning for a supervised living residential program in the future. The Center opened the only non-hospital based inpatient rehabilitation facility (26 beds) in the St. Louis area which provides treatment strictly to persons with head injuries. The facility offers a variety of comprehensive services for patients requiring more than traditionally offered in nursing home settings. The Center accepts persons with the ability to pay or who have access to third party pay.

Structured Residential Placement

St. Louis State Hospital, a facility operated by the Missouri Department of Mental Health, has developed a head injury unit to serve some head injury patients with aggressive or severe behavior problems. The unit is for men only as the facility does not have the staff to develop a separate program for both men and women. The unit is housed on a ward at the hospital and was originally established to serve the hospital's patients with head injury who had been at the hospital for some time and did not benefit from treatment for mentally ill patients. Some of the patients have been discharged and the unit now accepts referrals.

The Department of Mental Health and the Department of Health is developing an interagency agreement which will define the level of disability and behavior accepted by the Missouri Rehabilitation Center and the St. Louis State Hospital and how both facilities will coordinate services.

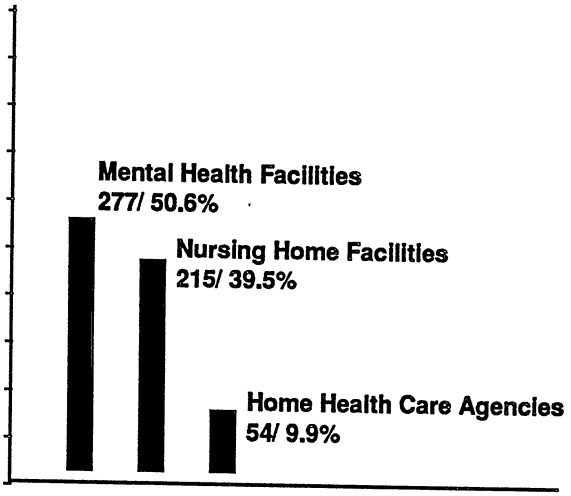
Persons with head injury who also exhibit aggressive and inappropriate behavior find it difficult to locate programs which will accept them due to lack of staff or adequate facility or both. The commitment law which allows the court to commit mentally ill persons who are considered dangerous to self or others does not apply to persons with head injury. Other than St. Louis State Hospital, there is no program in Missouri which considers itself a program designed for severe behavior problems.

Persons who require such a program tend to be shifted from facility to facility. Others who are not able to access any program tend to be difficult for the family and the community to manage.

Coma Management Programs

Although the Missouri Rehabilitation Center has a few clients who are comatose or in a semi-coma, the facility has not held itself out as having a coma management program. A few nursing homes have accepted patients coming out of coma, but generally the nursing home industry does not believe nursing homes have the staff, in part, due to the costs and reimbursement, to handle this level of care and to provide appropriate rehabilitation. St. John's Hospital in St. Louis has recently developed a coma management unit and SSM Rehabilitation Institute and Rebound, Inc. accept coma patients. Some families seek programs out of state for such care.

In January 1986, surveys were sent to the Department of Mental Health facilities, nursing homes and home health care agencies. A total of 547 persons with head injury were reported as being served by the various programs. Of the 277 served by the Department of Mental Health, 92 were served by psychiatric programs and 185 by programs for the mentally retarded or developmentally disabled.



Support Services

Recreation

The Missouri Head Injury Association sponsors a camp, Wilderness Retreat, during the summer with some assistance from the state through a contract with the Missouri Office of Administration, Division of General Services. The camp, which consists of two one-week sessions, not only provides socialization and recreation for those who have sustained a head injury, but also provides respite for their families and caretakers. The Bi-State Bi-State Chapter of the Association also offers a karate class for persons.

Counseling/Family Support/Referral

Some families and persons with head injury seek counseling services through community mental health centers throughout the state. The Missouri Head Injury Association through its local chapters offer family support and referral services. The council also provides referral services.

The rehabilitation programs, especially functional and transitional living programs, work closely with families and involved them in the rehabilitation process. Some of these programs have also established peer support groups so that persons with head injury can meet periodically to discuss their injuries and success or problems encountered on the job, in school, at home or during activities of daily living.

Case Management & Program Planning

Ideally, case managers for persons with head injury would be available throughout the state to assist families and survivors in accessing services and funding necessary for the client to receive rehabilitation and/or to remain in the community. Although case management services are provided by some individual providers, case management is not provided, generally, independent of providers for persons with head injury. For persons who meet the eligibility criteria for the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, case management services are provided through the division's eleven regional centers for the developmentally disabled. However, services which may be prescribed by the regional centers' treatment team may not be available for persons with head injury or clients with head injury may be referred to programs for persons with developmental disabilities.

Program Evaluation

Programs under contract with the Missouri Office of Administration, Division of General Services, are required to develop and implement individual treatment/rehabilitation plans according to guidelines provided in the contract. Facility standards with regard to fire and safety are also included in the contracts for programs to meet.

The Commission on Accreditation of Rehabilitation Facilities has developed standards for brain injury rehabilitation (acute and outpatient) programs and facilities may subscribed to the standards.

The Missouri Department of Social Services licenses nursing homes and the Missouri Department of Health licenses hospitals and rehabilitation hospitals. The Department of Mental Health licenses residential facilities serving persons with mental retardation and day programs serving either persons with developmental disabilities or mental illness. There are no state standards or licensing requirements for residential programs, day programs or other programs serving clients with head injury.

Chapter Two:

ACTION PLAN UPDATE

Summary

In keeping with the council's bylaws, the Missouri Head Injury Advisory Council held five meetings during Fiscal Year 1988. At its September meeting the council elected David B. Collins as chairman and Judith A Ferguson as vice-chairman. During mid-year, Judith Ferguson was elected to fill the office of chairman after it was vacated by Collins who had resigned. Representative Sheila Lump was elected to serve as vice-chairman. Four committees were appointed to carry out the goals and objectives of the council as outlined in the Fiscal Year 1987 Annual Report.

Some of the highlights of the year include: Expansion of Missouri's Medicaid program to include comprehensive day rehabilitation for post trauma patients; approval of the Community and Home Based Medicaid Waiver developed by the Missouri Department of Mental Health which is to include some clients or potential clients with head injury; development of a survey questionnaire to determine Missourian's awareness of head injury and prevalence of head injury; public hearing to assist in determining service priorities; survey of service providers in order to develop a service inventory/directory; and the establishment of a Task Force on Service Delivery Systems Recommendations to study the need for a division of head injury.

Issue 1: Prevention

Background

The incidence and severity of head injury can be reduced through prevention and early intervention activities. Half of all head injuries are caused by automobile accidents. The other half are are due to recreational accidents, assaults, weapons, falls, and industrial accidents. Injuries have traditionally been viewed as unavoidable accidents rather than a health problem. Yet, injuries are the leading cause of death and disability in children and young adults and cause the loss of more working years than all forms of cancer and heart disease combined.

Three general strategies are available to prevent injuries: (1) Persuade persons at risk to alter their behavior, (2) require individual behavior change by law or administrative rule and (3) provide automatic protection by product and environment design. In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma (injury) by the National Academy of Sciences. The committee issued a report in 1985, *Injury in America: A Continuing Health Problem.* One of the findings of the committee was the lack of date necessary to allow for the study of the epidemiology of most injuries. There is no national mechanism for collecting data regarding the number of head injuries, causes, number of persons disabled due to head injury and so forth. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

Also addressed in the report is the need for good emergency medical systems and medical treatment. The outcome of injury depends not only on its severity, but also the speed and appropriateness of treatment. In order to minimize injury, it is important to have a system in place which can allow for injury management at the scene of the accident and facilitate rapid delivery of the patient to a hospital which can provide the needed care.

Often referred to as the "golden hour," medical care provided to the patient during the sixty minutes following the accident is critical and often determines whether the patient survives the injuries. Designated trauma centers are vital to the system. Once a severely injured person arrives at a hospital, he or she will generally need the services of various specialists experienced in injury management.

The University of Missouri-Kansas City in cooperation with Argus Computing, Inc. developed a pilot trauma/injury

database January 1986. Three hospitals participate in the Kansas City project and record all trauma, not just head trauma. The UM-KC project was developed independently of the Missouri Head Injury Advisory Council. The project staff, however, are very cooperative and supply data to the council on request. The staff also participated in the development of the state reporting form for the head and spinal cord injury registry and assisted the Department of Health with the in-service training for hospital personnel with regard to the completion of the form.

Missouri has several laws designed to reduce fatalities and injuries. These laws include: Mandatory child restraints, mandatory seat belts for passengers in the front seat of automobiles, mandatory helmets for motorcycle riders, and stiff penalties for DWI (Driving While Intoxicated). Legislation passed during the 1988 session addressing safety for riders of ATVs (all terrain vehicles). Legislation also passed during the session repealing the sunset provision of the seat belt law.

There are several education programs promoting safety habits conducted by local and state agencies including: Missouri Division of Highway Safety, Missouri State Highway Patrol, Missouri Safety Belt Coalition, Missouri Safety Council, and the Missouri Head and Spinal Cord Injury Prevention Project conducted by the University of Missouri-Columbia.

Accomplishments

The Missouri Head Injury Advisory Council co-sponsored with the University of Missouri a conference on prevention October 1985. The conference allowed for the discussion of Missouri's ability to gather data, its emergency medical services program, trauma center status, and programs focusing on prevention activities.

During the 1986 legislative session, the council initiated legislation, which passed, mandating hospitals to report head and spinal cord injuries to the Department of Health, which in turn, is to report head injury data to the Missouri Head Injury Advisory Council. (The council was established under the legislation.) During FY'87, the council worked with the Department of Health and others to develop the reporting form. The registry was implemented by the department July 1, 1987. The department has provided in-service to the hospitals with regard to completion of the form and has continued to work with the hospitals to obtain consistency in reporting. The department will collect the data on a calendar year basis and will report accordingly.

During FY'88, the council initiated a head injury survey conducted by the University of Missouri, School of Journalism, Bureau of Media Research. The Bureau is conducting a statewide telephone poll to determine Missourians' level of knowledge of head injury, its causes and consequences. The poll may provide prevalence data which has not been determined in Missouri. The survey results are to be available during the fall of 1988.

The council studied Missouri's voluntary trauma center system during FY'86. The council initiated legislation, which passed, during the 1987 session which establishes and regulate trauma centers. It also instructs ambulances to bypass the nearest hospital in order to transport a severely injured patient to a trauma center, further defines what EMTs may do at the scene of an accident for a seriously injured victim and requires licensure for air ambulances.

The council has supported the Missouri Head and Spinal Cord Injury Prevention Project in its efforts to inform public school students as to the need for exercising caution and good judgment in order to prevent unnecessary injuries. The council has advocated for federal funding and for state funding to evaluate the effectiveness of the program and to expand the program. During the 1988 session, the council co-sponsored with other safety groups a breakfast for legislators featuring the prevention project. Members of the council testified before the Missouri Board of Health and the House Appropriations Committee on Mental Health for state funding for the program.

Also, the council networks with other safety groups with prevention efforts including the Missouri Division of Highway Safety Missouri Safety Council and the Missouri Safety Belt Coalition, of which the council is a member. In June 1986 the council director and two council members addressed the state and local safety councils as to how to use head injury data in their safety campaigns. The council also worked with the various safety groups

to compile information supporting helmet and seat belt use. The sunset provision of the seat belt law was repealed during the 1988 session. The council has joined the national campaign, 70 by 90, which is striving to meet 70 percent correct child safety seat and adult safety belt use by 1990.

Since January 1986, the council has published a newsletter called the *Quarterly.* It has sponsored three major conferences held annually in the spring beginning 1986: *Head Injury: Meeting the Challenges, Head Injury: Focus on the Future,* and *Head Injury: From Injury to Independence.* The council has developed a brochure and display board to use at conferences. The council maintains resource files and distributes information on request. Council staff arranged the Governor's proclamation proclaiming October as Head Injury Awareness Month and the proclamation and the Missouri House of Representatives and Senate courtesy resolutions honoring the Run to Daylight campaign, a head injury awareness project conducted on behalf of the National Head Injury Foundation. Council staff served as chairman for the Jefferson City ceremony and council chairman, Judith Ferguson, was a featured speaker.

Plan Initiatives

Public Safety Legislation

One-Year Goal: To support legislation which reduces fatalities and injuries.

First Year Objectives **Fiscal Year 1988**

1. To continue to oppose the helmet repeal.
2. To continue to oppose the seat belt repeal.
3. To continue to support legislation prohibiting children from riding in the back of pickup trucks.
4. To continue to study the issue of seat belts for school buses.

Progress in Meeting FY'88 Objectives: The council supported legislation repealing the sunset provision of the seat belt law, opposed the helmet repeal legislation, and supported legislation prohibiting children from riding in the back of pickup trucks. The council and other safety organizations put together a brochure regarding motorcycle helmets. At one of its meetings the council reviewed material, including a news segment, on seat belts for school buses.

One-Year Goal: To promote ATV (all-terrain vehicle) safety.

First-Year Objectives **Fiscal Year 1988**

1. To gather information from the registry and other data sources to determine the number of children and adults serious injured as the result of ATVs.
2. To study legislative options for promoting ATV safety (i.e. helmets,

age requirements, licensing, banning from public roads and highways, etc.).

3. To draft legislation regarding ATV safety and/or support legislation drafted by others.

Progress in Meeting FY'88 Objectives: The council relied on information gathered from the Missouri Division of Highway Safety and the Missouri Safety Council to support its position to assist with the passage of the ATV legislation which requires riders under the age of 18 to wear helmets, prohibits riders from riding on public roads, requires children to be supervised by an adult, and prohibits more than one rider on an ATV. The bill passed during the 1988 session.

Public Information & Education

Two-Year Goal: To inform the public of the causes and treatment/ rehabilitation of head injuries.

First-Year Objectives **Fiscal Year 1988**

1. To continue publishing the newsletter, press releases and other informational materials.

2. To maintain a resource file on current literature and audio-visual materials.

3. To continue to support funding to allow the Missouri Head and Spinal Cord Injury Prevention Project operated by the University of Missouri-Columbia to expand statewide.

Progress in Meeting FY'88 Objectives: The council met the above objectives. The council co-hosted with the Missouri Division of Highway Safety, Department of Health, Missouri Safety Belt Coalition, the Missouri Head and Spinal Cord Injury Prevention Project, and the Missouri Safety Council a breakfast for legislators to provide the opportunity to view the award winning film, *Harm's Way*, which features Missourians with head and spinal cord injuries and to learn about the Missouri Head and Spinal Cord Injury Prevention Project. The council testified before the Missouri Board of Health in support of additional funding within the budget of the Department of Health for the program and before the House Appropriation Committee on Mental Health and Health. The Department of Health received $10,000 (GR) to expand the program. This represents the first state money toward the program which also receives federal funds from the Prevention Health Block Grant administered by the department and federal funds from the Division of Highway Safety as well as funding from other private agencies.

The council continued publishing the newsletter, issued press releases, and appeared on radio and television news segments. The council participated in the proclamation signing proclaiming October as Head Injury Awareness Month and assisted with the Run to Daylight educational campaign conducted by a runner on behalf of the National Head Injury Foundation. The council also arranged for a state senatorial resolution recognizing February 7-13 as National Child Passenger Safety Awareness Week. The council staff presented information regarding the council and service needs at a legislative luncheon sponsored by

the Truman Medical Center-East and also attended a legislative luncheon hosted by the Rehabilitation Institute, Kansas City.

Second-Year Objectives **Fiscal Year 1989**

1. To develop a speaker's bureau in coordination with the Missouri Head Injury Association.
2. To develop brochures regarding the incidence and causes of head injuries in Missouri.
3. Issue press releases and other materials reflecting the data from the registry.
4. To encourage other organizations promoting safety to incorporate facts on head injury along with fatalities in their educational efforts.
5. To encourage school districts to invite the Missouri Head and Spinal Cord Injury Prevention Project to conduct its program during school assemblies.

Two-Year Goal: To determine incidence and prevalence of head injury.

Incidence of Head Injury

Second-Year Objectives **Fiscal Year 1989**

1. Using data from the trauma registry, determine the primary causes of injuries in Missouri, the number of injuries, the severity of injuries, and possibly the prevalence of head injury.

Progress in Meeting FY'89 Objective: The Office of Administration, Division of General Services, at the direction of the council entered into contract with the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to conduct a statewide poll. The results, to be available in the fall of 1988, should provide some prevalence data. The council developed the questionnaire which the Bureau is carrying out.

Three-Year Goal: To determine effectiveness of prevention programs.

Effectiveness of Prevention Programs

Third-Year Objectives **Fiscal Year 1990**

1. Using registry data and other informational systems, study the effectiveness of prevention programs and legislation designed to prevent injuries and fatalities.
2. Work with the University of Missouri - Columbia to study effectiveness of the Missouri Head and Spinal Cord Injury Prevention Project.

	Progress in Meeting FY'90 Goal: The council has written several letters supporting grant applications submitted by the Department of Health and the University of Missouri-Columbia for purposes of evaluating the effectiveness of prevention programs, specifically the program conducted by the University. None of the applications have been funded. The council continues to support the Missouri Division of Highway Safety and the Department of Health in their quest to obtain funding to link five data systems which would allow the study of injuries and the effect of prevention activities. The five data systems include: Missouri Head and Spinal Cord Injury Registry, Statewide Trafficway Accident Reporting System (STARS), Missouri Ambulance Reporting System (MARS), Hospital Admissions System, and the Death Certificates System.
EMS & Trauma Care	**Third-Year Objectives** **Fiscal Year 1990** 1. Using data from the registry, work with the Department of Health and the State Emergency Medical Services Council to study the effectiveness of Missouri's emergency medical system and the trauma center system.

Issue 2: Planning for a Statewide Service Delivery System

Background

Programs for survivors of head injury and their families are relatively new with the majority of programs, mostly private, having been developed the past ten years. No state has developed a statewide service system. Although Massachusetts claims to having been the first state to have a state program for persons with head injury, Missouri began head injury services (contractual) at the same time and the council was actually created three months earlier. The state of Missouri began addressing the lack of services in 1985 by creating the Missouri Head Injury Advisory Council on March 5, 1985, upon the recommendations of the Joint Interim Committee on Head Injury, a joint legislative committee which held statewide hearings in 1984 and issued a report January 1985.

An appropriation was made in the supplemental appropriation bill to the Office of the Administration for staff and necessary expenses for the council, which was charged with the responsibility of studying and making recommendations for improving services for persons with head injury. The council was administratively assigned to the Office of Administration as the problems and service needs associated with head injury crosses several agencies, yet no state agency has primary responsibility for providing services. The Office of Administration provides a forum for the different state agencies along with consumers, parents and other professionals to coordinate and to plan for state services.

For Fiscal Year 1985 appropriations were made to the Department of Health for head injury services. The Missouri Chest Hospital, a department facility, was changed to the Missouri Rehabilitation Center. A head injury unit was established representing the first state operated program created specifically for survivors of head injury. State funds were also appropriated to the department to purchase services for persons with head injury. (The appropriation was transferred to the Office of Administration, Division of General Services, July1, 1987, in order to coordinate services with the service recommendations of the council.)

Departments, other than the Department of Health, which offers programs or services which persons with head injury may be eligible for include: Department of Elementary Secondary Education, Division of Special Education (special education and the sheltered workshop program), Division of Vocational Rehabilitation (general rehabili-

tation, personal care assistance program and supported work program); Department of Social Services, Division of Family Services (Medicaid eligibility determination and determination for other entitlement programs), Division of Medical Services; and Department of Mental Health, Division of Mental Retardation-Developmental Disabilities and the Division of Comprehensive Psychiatric Services. There are also several local and private agencies which contract with the state departments to provide a variety of services. The Department of Public Safety through the State Highway Patrol and the Division of Highway Safety promotes highway safety in order to prevent and reduce fatalities and injuries.

Many fields use a case management system to coordinate and monitor all services to meet the full range of needs of an individual client. Case management can include the following general functions: (1) outreach, (2) intake, (3) assessment, (4) service plan development, (5) service coordination, (6) advocacy, (7) crisis intervention and (8) monitoring. The purpose of case management is to ensure that clients receive appropriate services. Although some head injury programs, medical programs, insurance, mental health, vocational rehabilitation and others use a case management service within their own programs, there is not a statewide case management system independent of providers for survivors of head injury. Such a system would allow for coordination of services which may be provided by different agencies.

Since the state has become more involved with the provision of services and with the head injury population, good planning is essential in order to maximize resources and reduce potential duplication. Planning includes identifying the service population, the determination of service needs, identifying gaps in the service system, prioritizing services and determining how to develop and to distribute them to ensure overall accessibility and availability.

Accomplishments

The council provided assistance to the Department of Health and the Office of Administration, Division of Purchasing, in developing Request for Proposals for the head injury service appropriation awarded to the department for FY'86. (For FY'86, $500,000 was appropriated.) The council viewed the process as an opportunity for providers to develop innovative approaches for services. During this process, it was noted by the council that there was a lack of common terminology for programs and services and differing perceptions as to how services should be provided.

To assist with program planning and development the Missouri Head Injury Advisory Council first defined head injury and services which may be needed. At that time (fall 1986), even the National Head Injury Foundation had not developed a definition for head injury. After reviewing definitions used by some states, the council defined the term "head injury". This definition was included in the legislation establishing the head injury register and the council, which passed in the 1986 legislative session.

Also during FY'86, the council identified and defined services and programs which may be needed starting with acute brain injury rehabilitation, functional living rehabilitation, transitional living, residential, case management and community support services. The report, *Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury,* was distributed statewide for comment. For FY'88 head injury contracts, these definitions were incorporated in the Request for Proposals.

During FY'87, the council through its committees, developed its *Action Plan* containing goals and objectives for developing and improving services. This plan was included in the FY'87 *Annual Report* and became the guide for its activities. The goals and objectives are now a part of each annual report.

Also during FY'86, the council conducted a survey to determine how many persons with head injury have sought services from the Department of Mental Health facilities and community programs as well as from nursing homes and home health care agencies. The report, *Survey of Missourians with Severe Head Injury Served by Mental Health, Home Health & Nursing Home Facilities,* indicated that persons are being served to some degree. Most of the persons receive maintenance services, but few receive specific treatments directed at brain injury induced deficits. Over half of the persons surveyed will still need services in five years. The lack of a state statutory

definition at that time presented some limitations. To be eligible for services by the Missouri Department of Mental Health, Division of Comprehensive Psychiatric Services or the Division of Mental Retardation and Developmental Disabilities, persons must fit the definition of mentally ill, mental retardation, or developmentally disabled and require the services offered by the department. Persons admitted or placed by the department are usually diagnosed accordingly .

On January 19, 1988, the council co-sponsored with the Office of Administration, Division of General Services, a public hearing to obtain recommendations for service priorities for the appropriation to the division for head injury services. Also,the division, upon the recommendation of the council, entered into a contract with the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to conduct a statewide poll to determine public awareness of head injury and possibly, the prevalence of head injury. The council developed the questionnaire and the University conducted a pilot project in June with the intention of completing the report by fall of 1988.

The council supported funding for additional staff for FY'87 for a head injury unit at St. Louis State Hospital. (The facility had previously identified patients believed to be head injured and who exhibited aggressive behavior in an attempt to provide more appropriate services.) The council believes that the Department of Mental Health has a role in treating persons with head injury who also exhibit severe and aggressive behavior problems. It has encouraged the department and the Department of Health, Missouri Rehabilitation Center, to develop an interagency agreement in order to coordinate services between the two facilities. The council has also advocated for additional funds to expand the head injury unit at Missouri Rehabilitation since its creation in FY'86 and to expand community services under contract with the Office of Administration. The appropriation for FY'87 for head injury services (contractual) was reduced to $272,000 and for FY'88 was increased to $314, 685 (and was transferred to the Office of Administration, Division of General Services).

The Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, agreed to include some of its eligible clients or potential clients of the division who are disabled as the result of a head injury under the Medicaid Waiver approved by the federal government for implementation beginning July 1988. The three-year waiver allows federal Medicaid reimbursement for nine home- and community-based services for eligible clients of the Department of Mental Health with developmental disabilities. The waiver is to initially be implemented in certain counties in five service catchment areas.

The council chairman appointed a Task Force on Service Delivery Systems Recommendations May 1988 to study and to recommend which agency should have primary responsibility for serving persons with head injury. The Task Force is to give a preliminary report at the September 1988 council meeting.

Plan Initiatives

Service Catchment Areas

One-Year Goal: To define service catchment areas for geographic distribution of services.

First-Year Objectives **Fiscal Year 1988**

1. To study service catchment areas used by other agencies for program delivery and planning purposes.
2. To define catchment areas taking in consideration population, accessibility by highway system, accessibility to medical trauma centers and rehabilitation programs.
3. To study integration of a case management system.

Progress in Meeting FY'88 Objectives: The council chairman appointed a Task Force on Service Delivery System in May, 1988, to study and to make recommendations as to the establishment of a division in a state agency responsible for a continuum of services for survivors of head injury and their families. Service catchment areas will probably need to be defined by the designated agency as most state agencies have defined catchment ares for various programs and purposes. The service entry point (county, district, or regional office, for example) will also need to be defined by the agency having primary responsibility for serving persons with head injury.

Office of Administration Head InjuryContracts

One-Year Goal: To determine the most effective use of contract monies appropriated to the Office of Administration, Division of General Services.

First- Year Objectives **Fiscal Year 1988**

1. To develop evaluation and monitoring tools for programs under contract with the Office of Administration, Division of General Services, Head Injury Section.
2. To monitor and evaluate programs under contract with the Missouri Office of Administration during FY'88.
3. To review FY'88 monitoring reports and the evaluations provided by the Department of Health for FY'86 and FY'87.
4. To review the RFP issued in FY'86 to solicit contracts to see if revisions need to be made.
5. To develop RFPs for FY'89 (starting July 1, 1988) based on council priorities and monitoring/evaluation reports of previous contracts.

Progress in Meeting FY'88 Objectives: A monitoring tool was developed and some of the programs were monitored by council staff.

Assess Service Needs

Three-Year Goal: To assess service needs.

First-Year Objectives **Fiscal Year 1988**

1. Rank service needs based on council knowledge and/or in consultation with other organizations.
2. To develop or to assist others to develop a tool or method to assess service needs comprehensively.
3. To develop an inventory of services currently provided.

Progress in Meeting FY'88 Objectives: A public hearing was held by the Office of Administration, Division of General Services, in cooperation with the Missouri Head Injury Advisory Council January 19, 1988, in Jefferson City to obtain input as to service priorities. The council developed a survey questionnaire to obtain information regarding public awareness of head injury, prevalence of head

injury, and service needs. At the recommendation of the council, the Office of Administration, Division of General Services, contracted with the University of Missouri School of Journalism, Bureau of Media Research. The Bureau conducted a pilot study in June and the full report is due fall of 1988. In order to develop a service inventory/directory a survey was sent to known head injury providers, nursing homes and hospitals. The directory is to be published in the fall of 1988.

Second-Year Objectives **Fiscal Year 1989**

1. To continue comprehensive assessment of needs.

2. Work with the Department of Health to develop research projects for purposes of assessing needs utilizing registry data.

Third-Year Objectives **Fiscal Year 1990**

1. To continue or to support research projects.

2. To rank service needs by service catchment area based on survey results, current services provided and data from head injury registry.

Roles of State Agencies

Three-Year Goal: To determine roles of existing state agencies in providing directly or indirectly services to survivors of head injury and their families.

First-Year Objectives **Fiscal Year 1988**

1. To review eligibility criteria for services from the Department of Mental Health, Department of Elementary and Secondary Education, Department of Health and Department of Social Services.

2. To discuss with each department or appropriate division director what services are to be provided and the eligibility criteria for those programs.

Interagency Agreements

Second-Year Objectives **Fiscal Year 1989**

1. To develop agreements as to how services are to be provided and alternatives for departments when the department's services are not appropriate.

2. To develop a referral system for state agencies and non-state agencies.

Third-Year Objectives **Fiscal Year 1990**

1. To determine which, if just one, state agency should have primary program responsibility for survivors of head injury.

Progress in Meeting FY'88-90 Objectives: Presentations were made before the council with regard to eligibility and services provided through the Division of Vocational Rehabilitation; Medicaid program which is administered by the Department of Social Services, Division of Medical Services; St. Louis State Hospital, a Department of Mental Health facility; and the Medicaid Waiver program administered by the Department of Mental Health, Division of Mental Retardation-Developmental Disabilities. The Department of Health, Division of Health Resources, provided an update on the head and spinal cord injury registry and the implementation of the trauma center legislation.

The council encouraged the Department of Health, Missouri Rehabilitation Center, and the Department of Mental Health, St. Louis State Hospital, to develop an interagency agreement so as to coordinate services. The departments are in the process of developing an agreement.

The council chairman appointed a Task Force on Service Delivery Systems Recommendations to study and to recommend which agency should have primary responsibility for serving persons with head injury.

Case Management

Five-Year Goal: To develop a case management model system.

First- through Fifth- Year Objectives **Fiscal Years 1988-1992**

1. To study philosophy and cost benefit of a case management system independent of service providers.
2. To work with the University of Missouri-Columbia should the University receive funding for its grant application to develop a pilot project for case management.
3. To work with the Department of Mental Health to establish a pilot project under the Medicaid waiver.
4. To develop budget requests for case managers based on the council's study.

Progress in Meeting FY' 88-92 Objectives: The council wrote a support letter for the University of Missouri-Columbia project, but the project did not receive funding. The Task Force on Service Delivery Systems is studying how case management can be delivered as a part of the service system. The Office of Administration is considering a FY'1990 budget request for a case manager for the head injury program.

Issue 3: Rehabilitation Services

Background

Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury can range from full time care to community re-integration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care before they benefit from rehabilitation. Many persons require more than one type of treatment simultaneously. Thus, services must be flexible, but also allow for the most frequent progressions.

Most often, after traumatic brain injury, the survivor goes from acute medical care to rehabilitation. This first rehabilitation, or Acute Brain Injury Rehabilitation, focuses on physical and gross cognitive deficits. This intensive rehabilitation program provides comprehensive goal directed rehabilitation services. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive, and behavioral function. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Functional living rehabilitation provides intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. Emphasis on this program is on functional cognitive, memory, or perceptual deficits, and appropriate interpersonal skills. Speech and language therapy, occupational and/or physical therapy are usually provided. Services may be delivered on an inpatient (residential) or outpatient (day program) basis.

Transitional living programs provide intensive rehabilitation with goal directed services to persons who have sustained traumatic head injury and who have completed acute and functional living rehabilitation programs or who have no significant need for those services. Emphasis in this program is on living in an independent situation. In this program, participants would typically move from close observation and supervision to independent living with minimal supervision. Transitional living programs may exist independently or may be part of a larger program. The program should provide safe, accessible housing which allows transition from group living situations to independent living. Housing facilities should include provision for 24 hour supervision.

Rehabilitation programs for persons with head injury are relatively new. Private programs have developed across the country over the past ten years, usually focusing on coma management, functional living rehabilitation, and/or transitional living programs. A few companies have began developing supervised living programs. These programs generally rely on patients/clients who have the ability to pay. In some states, head injury programs have been able to be reimbursed under the state's Medicaid program for certain services. For those persons who do not have the ability to pay, whose insurance will not cover the services, whose insurance has been exhausted, or do not have any other source such as Worker's Compensation, rehabilitation services are extremely limited.

Many persons who suffer from a head injury may return to employment. Others, with vocational or pre-vocational rehabilitation—which may be in addition to rehabilitation as described above, may return to employment. Still, others will need either supported employment or sheltered employment or day programs after rehabilitation. Day activity programs in this sense would maintain the intellectual, emotional, social, vocational and physical capacity of persons who are not able to maintain any type of employment. The program has a different purpose than a day treatment (functional living rehabilitation or transitional living) program.

In Missouri, the state provides some rehabilitation services through the Missouri Rehabilitation Center and through state contracts with the Office of Administration. In addition, The Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation, provides vocational rehabilitation services for

those persons who may be determined to be employable. For those persons who are not quite ready for vocational rehabilitation and do not need the intense level of rehabilitation provided in functional living rehabilitation, pre-vocational training may be needed. There are at least two programs which fit in this category: Blue Valley Industries, Kansas City, which is a new program dependent on private funding, and Advent Enterprises, Inc., Columbia, which is under contract with the Office of Administration to provide pre-vocational services. A day program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association and is under contract with the Office of Administration.

As the result of federal legislation, the Missouri Division of Vocational Rehabilitation administers the supported work program. Persons with head injury have been unable to access the supported work program due to lack of long term support services which are necessary in order to participate in the federal program.

Accomplishments

During FY'86, the council defined rehabilitation programs in terms of program setting, staffing and treatment/ rehabilitation considerations. A report was prepared and circulated statewide for comment. The definitions were incorporated in the Request for Proposal document issued by the Missouri Office of Administration, Division of Purchasing, soliciting proposals for contracts for head injury services.

In order to determine how many rehabilitation programs and the type of rehabilitation needed statewide, the council conducted a survey of programs available and being planned which will be included in a service directory. This information along with data gathered from the head and spinal cord injury registry and the council head injury survey conducted by the University of Missouri, Bureau of Media Research, will assist the council in assessing the need for various types of rehabilitation programs in order for persons to have access to such programs across the state. Programs providing functional living rehabilitation services as the result of state appropriations and programs such as Irene Walter Johnson Institute of Rehabilitation, St. Louis, which are not receiving state funding meet periodically to share program ideas and are developing a database.

The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injuries. The division provides ongoing in-service training regarding head injury to counselors. Part of the in-service training has included sending counselors and central office staff to the annual conferences sponsored by the council. Some of the division staff have assisted with presentations and with making suggestions for workshop topics.

The Missouri Head Injury Advisory Council initiated legislation introduced during the 1987 legislative session to allow sheltered workshops to receive a portion of the state subsidy for those clients who work less than six hours a day. This was introduced and passed to give the workshop staff flexibility to tailor the workshop program for those who may not be able to work a six hour day or who may require programming in conjunction with part time sheltered employment. Blue Valley Industries, Kansas City, has opened a pre-vocational program and a sheltered workshop program for persons with head injury. However, the Division of Special Education has refused to certify the program as a sheltered workshop as the division has operated under a rule which does not allow a sheltered workshop to be established to employ only one disability.

The Office of Administration, Division of General Services, contracts with Advent Enterprises, Inc., Columbia, for pre-vocational services and with Truman Center-East and Rusk Rehabilitation Center for functional living rehabilitation services. A day activity program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association with funding from the head injury services contractual appropriation which is now administered by the Office of Administration, Division of General Services. The program serves ten clients.

Rehabilitation Programs

Plan Initiatives

Five-Goal: To develop an array of rehabilitation programs accessible statewide.

First-Year Objectives **Fiscal Year 1988**

1. To include in the service inventory the number, location, eligibility requirements and type of rehabilitation programs currently available statewide.
2. To address rehabilitation programs in the needs assessment survey.
3. Determine the need for rehabilitation programs based on needs assessment survey, service inventory and trauma registry.

Progress in Meeting FY'88 Objectives: Surveys were sent to providers and other organizations to determine the extent services are being provided and if services are being planned for the future. The survey included requests for information with regard to service catchment area, eligibility criteria, and methods for payment.

First- through Fifth- Year Objectives **Fiscal Years 1988-1992**

1. Continue to determine the need for rehabilitation programs based on needs assessment survey, service inventory and trauma registry.
2. Prepare and submit budget request to establish a transitional living (residential) program.
3. Support expansion of the head injury programs, including the transitional living programs, at the Missouri Rehabilitation Center, Mt. Vernon.
4. Prepare and submit budget requests for other rehabilitation programs based on needs assessment.

Progress in Meeting FY'88-92 Objectives: Council members testified before the Missouri Board of Health and the Missouri Department of Health regarding the need for expanding the Missouri Rehabilitation Center. The council also testified before the Missouri House of Representatives Appropriation Committee on Mental Health and Health with regard to the Missouri Rehabilitation Center.

Program Coordination

Three-Year Goal: To promote coordination between acute hospitals and acute brain injury rehabilitation programs and between acute brain injury rehabilitation programs, functional living, transitional living programs and community support programs.

First- through Third- Year Objectives **Fiscal Years 1988-1990**

1. Distribute information regarding availability of services compiled as the result of the service inventory to social services department of hospitals.

2. Require programs receiving state funding from the Missouri Office of Administration, Division of General Services to have written agreements and/or policy regarding the relationships between the facility and rehabilitation programs, community support programs, acute hospitals and/or educational programs. The programs should be able to document the results of the agreements.

3. Conduct workshops regarding availability of services.

4. Promote awareness of programs through newsletter.

Progress in Meeting FY'88-90 Objectives: The Request for Proposals for head injury services required contractors to have written agreements between the facility and various programs. The council has encouraged the Department of Mental Health and the Department of Health to develop an interagency agreement with regard to St. Louis State Hospital and Missouri Rehabilitation Center.

The council newsletter, *Quarterly,* features head injury programs and services, both private and state programs. During the annual conference, 26 exhibitors displayed information pertaining to their programs and several program providers presented during the conference. The Missouri Rehabilitation Association dedicated an issue of its newsletter to head injury, the council and programs under contract with the Office of Administration. Council staff made presentations regarding services to the Consortium for Health Education, Kansas City, the Boone County Association for Retarded Citizens , Columbia, and, on a regular basis, to the Missouri Head Injury Association Board of Directors.

Pre-vocational & Vocational Rehabilitation

Three-Year Goal: To develop programs which offer pre-vocational, vocational and/or vocational rehabilitation services.

First-Year Objectives **Fiscal Year 1988**

1. Support the Division of Vocational Rehabilitation in its efforts to secure appropriate vocational rehabilitation services.

2. Participant on an advisory committee established by the Division of Special Education and others in studying the role and options for sheltered workshops, including the provision of pre-vocational and/or vocational training in addition to sheltered employment.

Progress in Meeting FY'88 Objectives: Council staff participated on an advisory committee on sheltered workshops established by the Division of Special Education to review the sheltered workshop law to see if the law is still meeting the needs and purpose of the sheltered workshop program. The committee was generally content to leave the law as it is The division has taken the position in the past that a workshop board can only be responsible for overseeing a sheltered workshop program and that a workshop can not also conduct other programs such as a pre-vocational or behavioral program in conjunction with the sheltered workshop program. That rule was not overwhelmingly challenged by the advisory committee.

Second- and Third-Year Objectives **Fiscal Years 1989-1990**

1. To encourage private/public institutions to develop vocational training programs for survivors of head injury.
2. Draft legislation, if needed, to allow state subsidy for those sheltered workshops who opt to provide training in addition to sheltered employment.
3. To determine the role of vocational education schools in providing vocational training to students who have suffered from a head injury.

Sheltered Employment

Three-Year Goal: Develop sheltered employment for employees who are handicapped due to head injury.

First- through Third-Year Objectives **Fiscal Years 1988-1990**

1. Work with the Division of Special Education and the advisory committee to determine how sheltered employment should be made available to survivors of head injury.
2. Encourage the establishment of sheltered employment for persons with head injury.

Progress in Meeting FY'88-90 Objectives: Council staff served on the sheltered workshop advisory committee. The sheltered workshop managers suggested that the council develop a "white paper" outlining how the council believed sheltered employment should be made available to persons with head injury (setting, staffing, type of work, separate facilities, etc.). The council Committee on Program Planning and Development reviewed the types of sheltered employment (benchwork model, enclave, mobile crew, etc.) and made some preliminary recommendations which have not yet been drafted for a paper.

Supported Work

Two-Year Goal: To develop supported work programs.

First-Year Objectives **Fiscal Year 1988**

1. Review the Division of Vocational Rehabilitation and other agencies plan for a supported employment initiative.

2. Survey the number of head injured who would benefit from supported work programs.

3. Participate with the Division of Special Education in determining the sheltered workshops' role, if any, in providing supported employment programs.

Progress in Meeting FY'88 Objectives: The Division of Vocational Rehabilitation made a presentation on supported work to the council at one of its meetings. Council staff met with the Governor's Core Policy Team on Supported Employment and the Team agreed that supported work would be beneficial to persons with head injury. Persons with head injury have been unable to access the supported work program as one of the federal requirements is that long term support must be available. The Team wrote a letter supporting a budget request for the Office of Administration, Division of General Services, for community support programs to enable persons with head injury to participate in the supported work program. The Division of Vocational Rehabilitation estimates that at least 30 clients could be served the first year.

Second-Year Objectives **Fiscal Year 1990**

1. Draft legislation, if needed, to address supported employment.

2. Work with the Division of Vocational Rehabilitation in accessing VR funds for supported employment for head injured clients.

3. Encourage the development of supported work programs.

Competitive Employment

Three-Year Goal: To develop employment opportunities.

First- through Third-Year Objectives **Fiscal Years 1988-1990**

1. To determine vocational training and skills needed in order for survivors of head injury to become employable.

2. To evaluate success of persons with head injury in returning to employment.

3. To recognize employers who have established exemplary programs for employing persons with head injury.

4. To develop informational brochures for employers regarding the benefits of hiring persons handicapped due to head injuries.

Day Activity Programs

Five-Year Goal: To establish day activity programs.

First- and Second -Year Objectives — **Fiscal Years 1988-1989**

1. Survey number of existing day programs or planned programs to be included in the service inventory/directory.

2. Determine need according to needs assessment.

3. Develop a model for day activity programs which address:

   (a) a definition/description of day activity programs including the qualifications of day program providers paid under state contract.

   (b) an array of day program services which should be available according to needs assessment and registry data.

4. Explore funding for adult day care.

5. Work with the Department of Mental Health to develop day care, personal care, respite and home/equipment modification under the Medicaid waiver.

Progress in Meeting FY'88-89 Objectives: The survey was completed and the directory will be developed by fall 1988. A definition for day (activity) program was included in the RFP issued by the Office of Administration, Division of Purchasing. Since the Medicaid waiver has been approved, the council will work with the Department of Mental Health, which has agreed, to schedule a meeting for potential vendors to enroll those vendors who wish to participate under the program.

Third- through Fifth-Year Objectives — **Fiscal Years 1990-1992**

1. Prepare and submit budget requests to expand day programs and other support services.

Issue 4: Services for Children

Background

Rehabilitation services for children are limited. Very few services are available to children with long term medical needs. However, legislation which passed during the 1988 legislative session allows for the establishment of nursing homes for children under the state Medicaid program. The legislation also expands Medicaid eligibility for children.

The Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, provides some services to children with head injuries and their families. The division considers a child to be developmentally disabled when the injury occurs prior to age 18 and the child functions similarly to those children with mental retardation or other developmental disabilities.

Accomplishments

The Missouri Department of Elementary and Secondary Education, Division of Special Education, has assigned staff to assist school districts to provide educational services to children with head injuries. The division has prepared a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury*, to be used in conjunction with the educator's manual prepared by the National Head Injury Foundation. The Missouri Division of Special Education has made the National Head Injury Foundation manual available to teachers upon request and encourages special educators to used the division's manual as a supplement. Films and other materials on head injury have been added to the Special Education Dissemination Center, University of Missouri-Columbia, a resource center for teachers and school administrators in Missouri who serve handicapped children.

The Department of Mental Health received approval for a Medicaid wavier which will allow reimbursement under the Medicaid program for community services for eligible or potential clients of the Division of Mental Retardation and Developmental Disabilities—including those who meet the division's eligibility requirements as the result of head injury. The waiver will include all ages provided they can also meet Medicaid eligibility.

Plan Initiatives

Services for Children

Five-Year Goal: To study and recommend appropriate rehabilitation, long term care, educational, respite and other support services for children with head injuries and their families.

First-Year Objectives — **Fiscal Year 1988**

1. Determine the service needs of children with head injury by a needs assessment survey.

	2. Survey number of existing planned programs for children to be included in the service inventory. ***Progress in Meeting FY'88 Objectives:*** Programs have been surveyed and the service directory should be available in the fall of 1988.
Role of Department of Mental Health in Serving Children with Head Injuries	**Second- through Fifth- Year Objectives** **Fiscal Years 1989-1992** 1. Study and recommend a model(s) for programs for children suffering from head injury. 2. Work with the Department of Mental Health to determine its role in providing services to children with head injuries.

Issue 5: Residential Services

Background

The goal of rehabilitation is to enable a person to return to his or her environment and to live as independently as possible. For those who are unable to live independently either within the family structure or alone, then some type of housing or support which provides supervision and protection may be needed. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting. Residential settings which may be needed include nursing facilities, structured residential placement for those exhibiting severe behavior problems and supervised living arrangements.

For others to live independently some assistance may be required such as personal care assistance, in home support, or home health care assistance. A family may need the benefit of respite care in order maintain a family member with a head injury at home. Respite care provides temporary relief or emergency relief to the family, thus enabling the family to care for the person at home.

Long term housing has yet to be developed specifically for survivors of head injury. Some individuals with head injury have been placed in community based residential facilities for persons with developmental disabilities, nursing homes, and habilitation centers and hospitals operated by the Department of Mental Health.

Accomplishments

During the FY'86, the Missouri Head Injury Advisory Council surveyed the number of survivors of head injury receiving services from the Department of Mental Health through its Divisions of Comprehensive Psychiatric Services and Mental Retardation and Developmental Disabilities, nursing homes and from home health care agencies. The survey noted that significant number were being served, although most were not receiving services specific to their injury related deficits.

The Department of Mental Health is proposing to include eligible head injury clients receiving services from the Division of Mental Retardation and Developmental Disabilities under a Medicaid waiver in an attempt to provide services more appropriately and in a less restrictive environment. Services proposed under the waiver include residential, respite, and home adaptation.

St. Louis State Hospital, a psychiatric facility operated by the Department of Mental Health, has established a unit for persons with head injury who also have severe behavior problems. The council has supported funding for the unit and has encourage the department to coordinate services with the Missouri Rehabilitation Center operated by the Department of Health.

Some nursing facilities have expressed interest in serving head injured persons who are comatose, semi-comatose or who have extensive medical needs, however, the state Medicaid reimbursement rate does not accommodate the costs of serving such persons

The Office of Administration, Division of General Services, contracts with Opportunities Unlimited, Inc., an independent living center in Columbia to provide in home support services. The Missouri Association of Head Injury sponsors Wilderness Retreat at the Lake of the Ozarks during the summer with funds, in part, from the Office of Administration, Division of General Services. The Retreat not only provides socialization/recreational opportunities for survivors of head injury, but also respite for their families.

Plan Initiatives

Two-Year Goal: Participate with the Department of Mental Health to obtain a Medicaid waiver and to implement the waiver, should it be approved.

Department of Mental Health Medicaid Waiver

First-Year Objectives **Fiscal Year 1988**

1. Assist the department in determining clients or potential clients with head injury who would be more appropriately served under the waiver.

2. Assist the Department of Mental Health in identifying potential provider for services approved in the Medicaid waver.

3. Assist the Division of Mental Retardation and Developmental Disabilities with the development of policy with regard to appropriate services for those clients who have suffered a head injury.

Progress in Meeting FY'88 Objectives: Staff from the Department of Mental Health met with the council throughout the year to discuss the waiver, eligible services and client eligibility. Starting July 1, 1988, the department will work with the council to identify persons who would qualify under the waiver.

Second-Year Objectives **Fiscal Year 1989**

1. Assist the Division of Mental Retardation and Developmental Disabilities by providing/arranging training to case managers with regard to evaluation/assessment, interpretation, and writing appropriate rehabilitation/treatment goals.

Coma, Semi-Coma Management Programs

Two Year Goal: To develop coma and semi-coma management programs.

First-Year Objectives **Fiscal Year 1988**

1. Survey and/or use registry data to determine the number of persons requiring coma/semi-coma care.
2. Support the Missouri Rehabilitation Center in developing either a coma or semi-coma management program.
3. Initiate a committee or task force to study the costs of coma management programs.
4. The committee once appointed, will study the necessary staffing and medical/equipment considerations for a coma management program.
5. The committee will look at existing rate structure under the Medicaid program, the Medicaid exception process, Medicaid waiver or other funding areas and make recommendations as to how coma/semi-coma management programs should be funded.

Progress in Meeting FY'88 Objectives: Members of the council testified before the Missouri Board of Health and before the House Appropriations Committee on Mental Health and Health supporting a semi-coma management program at the Missouri Rehabilitation Center.

During the 1988 legislative session a house resolution passed calling for a joint interim committee to study nursing shortage and the Senate appointed an interim committee to study nursing home issues. The council will follow the hearings of both of these committees and arrange testimony to address the lack of nursing facilities to provide care and rehabilitation for coma, semi-coma or persons who require intensive medical and rehabilitative care.

Second-Year Objectives **Fiscal Year 1990**

1. Introduce legislation, if needed, to implement coma/semi-coma management or other medically/rehabilitative intensive programs.
2. Develop standards, if needed, for the above programs.
3. Working with nursing home organizations, assist with staff training, if desired.

Behavior Management Programs

Three-Year Goal: To develop behavior management programs.

First-Year Objectives **Fiscal Year 1988**

1. Determine the need for a structured residential placement to be developed specifically for those with severe behavior problems.

2. Identify program costs needed for a program for severe behavior disorders.

Progress in Meeting FY'88 Objectives: The council requested staff from St. Louis State Hospital to meet with council at two of the council meetings in order to discuss the role of the state hospital in serving head injury patients with severe behavior problems. The council encouraged the facility and the Missouri Rehabilitation Center to meet and discuss the type of clients each facility serves and to develop an interagency agreement in order to coordinate services. The council believes that the Department of
Mental Health has a role in serving aggressive, potentially dangerous, and/or severe behavior problems, but that once the behavior is under control, the patient should then be referred to programs specializing in head injury for rehabilitation or other necessary services.

Second-Year Objectives **Fiscal Year 1989**

1. Identify eligibility criteria for those programs.

2. Identify potential providers for a behavior management programs.

3. Work with the University of Missouri-Columbia to develop in-service staff training workshop(s) designed to assist program (state and non-state) staff in managing aggressive behavior exhibited by head injured clients.

Third-Year Objectives **Fiscal Year 1990**

1. Prepare and submit a budget request to increase state funding for a pilot behavior management program.

Five-Year Goal: To develop supervised living arrangements for those who will continue to need supervision following rehabilitation.

Supervised Living Arrangements

First- and Second-Year Objectives **Fiscal Years 1988-1989**

1. To develop a model for supervised living arrangements addressing:

   (a) a definition/description of supervised living arrangements (apartment, group home), including staff requirements or other requirements.

   (b) an array of support services, including day programs or employment needed in conjunction with supervised living arrangements.

   (c)standards, including physical plant facility, safety, drugs and medications, record keeping and client rights.

2. To study similar residential alternatives available to persons with head injury in other states and similar programs offered to other population groups in Missouri.

3. Determine the number of persons with head injury who are in need of supervised residential programs.

Third-Year Objectives **Fiscal Year 1990**

Funding Options for Residential Services

1. Study and recommend how supervised living arrangements could be funded, both start up costs and operational costs.

2. Conduct a workshop on funding sources (HUD, Section 8, "S.B. 40", insurance and other sources) for supervised living arrangements.

Third- through Fifth- Year Objectives **Fiscal Years 1990-1992**

1. Locate potential providers for developing supervised living arrangements.

2. Assist potential providers in accessing funds.

3. Prepare and submit budget request to assist with funding for supervised residential programs.

Home Health Care/ Personal Care Attendant

Three-Year Goal: To expand usage of home health care and personal care attendant services.

First-Year Objective **Fiscal Year 1988**

1. To work with the Department of Mental Health to identify vendors who could provide home health care under the Medicaid waiver to clients with head injury should the waiver be approved.

Progress in Meeting FY'88 Objective: The council is working with the department to identify potential vendors.

Second-Year Objectives **Fiscal Year 1989**

1. To work with the Division of Vocational Rehabilitation to determine the number of persons with head injury who would be eligible for personal care assistance.

2. To work with the Division of Aging to determine how survivors of head injuries and their families could access home health care services through the division's programs.

3. Ask Missouri Association of Home Health Care Agencies and Hospital Home Health Council to include a session on the needs of persons with head injuries and their families at their annual conferences.

Progress in Meeting FY'89 Objectives: The council staff responded to a call for presentations for the 1988 conference held by the Missouri Association of Home Health Care Agencies offering to present along with staff from the University of Missouri-Columbia a workshop on head injury. The Association rejected the presentation proposal.

Third-Year Objectives **Fiscal Year 1990**

1. Based on needs on survivors of head injury for personal care assistance, work with the Division of Vocational Rehabilitation to obtain sufficient funding.

2. To develop a referral mechanism or resource document to include home health care agencies which could provide services to survivors of head injury and their families for hospitals, local health units, and physicians.

Respite Care

Three-Year Goal: To develop respite care.

First-through Third-Year Objectives **Fiscal Years 1988-1990**

1. To study various methods for providing respite care.

2. To study funding sources for respite care.

3. To develop a model for providing respite care.

4. To encourage providers to offer respite programs.

Family Support Services

Five-Year Goal: To develop an array of family support services.

First- through Fifth-Year Objectives **Fiscal Years 1988-1992**

1. To design an array of family support services to include, but not limited to, information and referral, counseling, evaluation, crisis stabilization, in-home rehabilitation, recreation and transportation.

2. To identify potential providers for various family support services.

Issue 6: Professional Training/Staff Development

Background

The demand for professionals experienced in working with survivors of head injury and their families will increase as programs and services are developed. Professionals will be needed in all areas including evaluation, case management, counseling, rehabilitation, community support programs and specialized programs such as behavior and coma management.

The Missouri Head Injury Association has the past six years sponsored statewide conferences for professionals and parents as has the Rehabilitation Institute, Kansas City, University of Missouri-Columbia and others.

Accomplishments

The Missouri Head Injury Advisory Council has sponsored three statewide conferences which included sessions designed for professionals as well as families and other interested persons. The Division of Vocational Rehabilitation specifically requested sessions for the division's counselors on neuropsychological evaluation and how to interpret the data to formulate employment goals during the 1987 annual conference sponsored by the council. The division has conducted several seminars for its counselors relating to head injury.

The Division of Special Education has assigned staff to work with school districts and teachers who have students with head injury. The division provides assistance to help teachers to develop appropriate educational plans based on evaluations. The Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, has agreed to work with the council to schedule an in-service training on evaluation and development of treatment plans for staff from the regional centers on developmental disabilities.

Plan Initiatives

In-Service Training/ Staff Development

One-Year Goal: Provide opportunities for professionals to expand knowledge on head injury rehabilitation.

First-Year Objectives **Fiscal Year 1988**

1. Conduct a spring conference to include topics such as research, medical, rehabilitation and community re-entry.

2. Work with the Department of Mental Health to assess in-service needs of mental health and mental retardation and developmental disabilities staff.

Progress in Meeting FY'88 Objectives: The council held its annual conference May 23-25 in Jefferson City. Over 200 persons attended. The council is working

with the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities to schedule an in-service training workshop.

Assessment Tools

Two-Year Goal: To encourage assessment teams to use functional evaluation tools with neuropsychological and medical assessment.

First- and Second-Year Objectives — **Fiscal Years 1988-89**

1. To study and recommend the development of an evaluation tool to assess the functioning level of a persons with a head injury.
2. Support in-service training/conference(s) to assist staff on how to assess functional level.

Behavior Management Training

Three Year Goal: To train staff as to how to manage behavior problems.

First- through Third-Year Objectives — **Fiscal Years 1989-1991**

1. To work with the University of Missouri-Columbia and/or other institutions to develop training packages for staff.
2. To conduct in-service workshops on behavior management.

Issue 7: Legal Issues

Background

As treatment, rehabilitation and other services for survivors of head injury are relatively new, many professionals, including the legal community, do not understand the deficits—such as cognitive, memory and judgment—that a victim of head injury may have. Such deficits may pose problems for head injured persons who are trying to meet the demands of daily living.

Sometimes the rehabilitation and care of a person with a head injury are often determined by the amount the person receives through a settlement related to the accident. It is important, therefore, for those representing the victim to understand the rehabilitative and, perhaps, the long term needs a person may have as the result of the injury.

Although certain types of disability or illness are addressed by law with regard to criminal actions, disabilities due to head injury are not. Persons considered dangerous to self or others may be involuntarily for psychiatric care if they are mentally disordered as defined by law or an alcohol or substance abuser as defined by law. A person suffering from a head injury who exhibits behavior which may be considered dangerous to self or others may be detained involuntarily under the provisions stated above for 96 hours. The mental health commitment law, however, does not pertain to persons who may be dangerous as the result of a brain injury. They cannot be detained beyond 96-hours unless they are determined to be mentally ill.

Another legal issue is the "right to die" issue. There are some instances where as the result of a severe head injury a person will remain in a vegetative state. Some parents or a spouse face a situation where the person will not regain conscious and is dependent on mechanical devices or feeding tubes to sustain life. Missouri does not have a "right to die" statute. The Missouri Supreme Court has agreed to review a case involving the disconnection of a feeding tube from a person with a head injury who is in a coma at the Missouri Rehabilitation Center.

Finally, some survivors of head injury may need protection or assistance in managing their fiscal affairs and/or personal affairs. It is important that the legal community understands how such protection could be provided under Missouri's Guardianship Code by a guardian or limited guardianship and/or a conservator or partial conservatorship.

Accomplishments

During the 1987 conference, "Head Injury: Focus on the Future," workshops on legal issues were offered. Topics included Missouri's Guardianship Code, involuntary detention and criminal law. The Missouri Bar Association has offered to sponsor a seminar on head injury through its continuing education program.

Plan Initiatives

Commitment Law

Three-Year Goal: To develop appropriate programs for those persons suffering from a head injury considered dangerous to self or others.

First- through Third-Year Objectives **Fiscal Years 1988-1990**

1. Work with the Division of Comprehensive Psychiatric Services, Department of Mental Health, to determine appropriateness of the commitment statutes and the Department of Mental Health programs to serve persons with head injury considered dangerous to self or others.

2. Determine the number of persons who would require this type of care and protection.

3. Study and make recommendations, if appropriate, regarding involuntary outpatient treatment legislation introduced during the 1987 legislative session.

Progress in Meeting FY'88-90 Objectives: Staff from the Department of Mental Health, Division of Comprehensive Psychiatric Services have met with the council to discuss in particular the role of St. Louis State Hospital and the Division of Comprehensive Psychiatric Services.

Five Year Goal: To propose "right to die" legislation.

"Right to Die" Issue

First- through Fifth-Year Objectives **Fiscal Years 1988-1992**

1. To study legislation from other state regarding the "right to die" issue.
2. To determine other organizations and professional groups which would also be interested in the "right to die" issue.
3. Draft legislation regarding the "right to die" concept.
4. Participate on the Task Force on Ethical Decision Making in Long-Term Care Facilities established by the Division of Aging.

Progress in Meeting FY'88-92 Objectives: The council supported legislation which would have allowed a person to designate a person to speak on his or behalf with regard to medical decisions to prolong life in the event the person is unable to make that decision due to his or her medical condition. The legislation failed to make it out of committee.

Three-Year Goal: To educate the legal system.

Seminar for Attorneys

First- through Third-Year Objectives **Fiscal Years 1988-1990**

1. To ask the Missouri Association of Trial Attorneys to include a session(s) on head injury, at its annual conference.
2. To ask the Missouri Bar Association to include a seminar(s) on head injury through its continuing education program.

Issue 8: Quality Assurance

Background

Since programs for survivors of head injury are relatively new, there are no state licensure or certification requirements for programs serving exclusively persons with head injury. (There are licensure/certification requirements for nursing homes and residential and day programs serving persons with mental illness, alcohol and drug abuse problems, mental retardation or other developmental disabilities.) The Commission on

Accreditation of Rehabilitation Facilities (CARF), which is a voluntary organization, has developed accreditation standards for acute rehabilitation programs. The National Head Injury Foundation is an associate member of CARF.

Accomplishments

During FY'86, the council defined acute, functional and transitional living programs based, in part, on CARF standards. These definitions along with some fire and safety standards taken from the Department of Mental Health licensure standards were incorporated in the Request for Proposals issued by the Division of Purchasing and are a part of the contracts the Office of Administration, Division of General Services, have with agencies providing services to persons with head injury. During the 1988 May conference, a featured speaker addressed programs standards and the standards developed by CARF.

Plan Initiatives

Program Standards

Five-Year Goal: To develop standards for head injury programs receiving state funds.

First- through Fifth-Year Objectives **Fiscal Years 1988-1992**

1. Study and make recommendations for program standards with regard to staffing, safety and treatment/ rehabilitation plans,

2. As standards are developed and are accepted, incorporate them into state program contracts (RFPs).

Progress in Meeting FY'88-92 Objectives: Some program definitions and safety standards were incorporated in the RFPs issued for FY'89.

Issue 9: Financial Support

Background

Head trauma usually results in large medical bills particularly in the person is hospitalized extensively and/or requires long term rehabilitation and care. Private insurance pays for at least partial acute care medical expenses. Many policies, however, do not cover rehabilitation, long term care, or complete hospital coverage. The state Medicaid program has strict financial guidelines which make it difficult for working families to be eligible. The program also is limited as to what services it will reimburse, and is particularly limited in reimbursing outpatient rehabilitation.

Some financial aid is available through Missouri Crippled Children's Services administered by the Missouri Department of Health. The program is to help financially eligible children under 21 obtain medical, rehabilitation and other services. The guidelines are broad enough to accommodate children with head injuries, but program funding is limited. The program has also been reluctant to fund psychological and cognitive rehabilitation. If a person can meet the eligibility requirements of the Department of Mental Retardation, Division of Mental Retardation and Developmental Disabilities, some services are available through the eleven regional centers for developmental disabilities.

There are three issues surrounding insurance. One issue is that many persons did not carry health care insurance prior to the injury. Therefore, many persons, particularly young adults, do not have insurance to pay for their medical care. Others may carry insurance, but find that their policies do not cover rehabilitation (outpatient) and/ or long term care. A third issue is that some survivors of head injury find that following their accidents, they are unable to find affordable health insurance as they are considered "high risk".

The costs associated with medial and long term care will often place financial hardship on families who have a member with a brain injury. Should a person not have insurance or should the insurance not cover all expenses and the persons or family does not qualify for Medicaid, there are not any state aid programs to assist with the medical expenses. The only state funded programs specifically for persons with head injury are through the Missouri Rehabilitation Center operated by the Missouri Department of Mental Health and through contracts with the Missouri Office of Administration, Division of General Services, and community agencies.

A Missouri House of Representatives committee studies health care issues during the interim in 1986. It recommended a "MedAssist" program to help those who were unable to obtain insurance to have a health care plan. During the 1987 summer interim, a joint legislative committee held hearings to address health care issues and issued a report. Legislation was introduced in the 1988 session for the third year to establish a health insurance program. The legislation did not pass. Also, the last three years legislation has been introduced to create a "high risk"pool in order for those considered "high risk" to be able to obtain insurance. The MedAssist concept and the high risk pool concept have been incorporated into an initiative petition calling for a constitutional amendment to be voted on November 8.

There are several programs (federal, state and local) which are targeted, in part, to programs for persons with handicaps or directly to handicapped persons. Such programs include HUD (Housing and Urban Development), Section 8 rental subsidy, SSI, Missouri Elderly and Handicapped Transportation Assistance Program, federal Developmental Disabilities program, Vocational Rehabilitation, supported work program, and county mill tax programs for persons who are or otherwise handicapped or developmentally disabled. Most of these programs have yet to be tapped by persons who are disabled due to a head injury or by programs providing head injury services.

Accomplishments

Council members testified before the interim house committee on health care regarding the needs of survivors of head injury. The council supported legislation to create a high risk pool and initiated legislation to create a catastrophic fund. During the 1987 session, legislation was introduced to allow voters to increase cigarette taxes to be used for a state catastrophic fund. The proposal failed to receive approval from the senate committee. A Senate Concurrent Resolution No. 6 passed during the 1987 session calling for a joint interim committee to study health care needs. The council staff represented the Office of Administration on the committee which was comprised of five senators, five representatives, public members and state agencies.

Senator Ed Dirck, council member, requested an attorney general's opinion as to whether programs providing services to persons with head injuries would be eligible to receive funding from county boards which administer revenue generated from a county tax for persons with handicaps and developmental disabilities. The opinion was that the programs would be eligible. The opinion was sent to all county boards and sheltered workshops. During the 1988 session, Senator Dirck sponsored legislation which would clarify that persons with head injury would be eligible. The bill did not pass and drew opposition from the mental retardation advocates.

Also, during the 1988 session, legislation sponsored by council member Representative Marvin Proffer passed expanding the Medicaid program. The bill expanded services to include comprehensive day rehabilitation for post acute trauma patients, to allow for the establishment of nursing facilities for children and expanded eligibility requirements for children.

Plan Initiatives

Health Insurance

One-Year Goal: For survivors of head injury to be able to obtain health care coverage.

First-Year Objective **Fiscal Year 1988**

1. To continue to support efforts to create a high risk pool or any other alternative to allow persons considered high risk due to a head injury to obtain health care insurance (i.e. MedAssist).

Progress in Meeting FY'88 Objective: The council supported the risk risk pool legislation and the legislation calling for a constitutional amendment to establish a state health insurance program for those unable to obtain insurance.

Expand Health Care Benefits

Three-Year Goal: To extend health insurance coverage.

First-Year Objectives

Fiscal Year 1988

1. To study present required coverage under Missouri law.
2. To study other states' requirements for health care coverage.

Second-Year Objectives **Fiscal Year 1989**

1. To study and to assess cost savings, if any, if coverage were extended to include rehabilitation.
2. To study costs of including long term care coverage in health policies.
3. To study benefits of including catastrophic coverage in health policies.

Third-Year Objectives **Fiscal Year 1990**

1. To meet with the insurance industry to discuss rehabilitation coverage.

2. To meet with business associations and organizations to discuss cost and cost benefits, in any, for including rehabilitation coverage in group policies.

Three-Year Goal: To expand Medicaid coverage.

Expand Medicaid Coverage

First- through Third Year Objectives **Fiscal Years 1988-1990**

1. Participate in public hearings to be conducted by Joint Interim Committee on Missouri Health Care Systems and other deliberations which may be considered by the Missouri General Assembly.

2. To work with the Department of Social Services, Division of Medical Services, to develop program criteria and state plan amendment for the new Medicaid service, comprehensive day rehabilitation, included in H. B. 1139 which passed during the 1988 session.

3. To continue to study state and federal options under the Medicaid programs.

4. To make the legislators aware of the needs of survivors of head injury which could be addressed under the Medicaid program.

5. To recommend changes in the Medicaid program in order to meet the medical needs of survivors of head injury.

6. To study the feasibility of obtaining a Medicaid waiver to cover persons who are disabled due to head injures.

7. To work with the Senate Select Committee on Nursing Home Problems to develop recommendations for developing a rate reimbursement sufficient to cover persons with head injury who have acute medical and rehabilitation needs.

Progress in Meeting FY'88-90 Objectives: Council staff participated as a member of the Joint Interim Committee on Missouri Health Care Systems. The council supported the adding of an amendment to a house bill to expand Medicaid to include comprehensive day rehabilitation services, which passed.

Catastrophic Coverage

One-Year Goal: To create program(s) to reimburse costs for catastrophic medical and rehabilitation care.

First-Year Objective **Fiscal Year 1988**

1. To participate and support the Joint Interim Committee on Missouri Health Care Systems in its efforts to study means of financing state programs to reimburse catastrophic medical and/or rehabilitation care.

Progress in Meeting FY'88 Objectives: The council supported the committees recommendations including a senate joint resolution calling for a constitutional amendment to allow the state to establish a health insurance program.

Access Local, State, & Federal Programs

Three-Year Goal: To access local, state and federal programs for persons with handicaps.

First- and Second-Year Objectives **Fiscal Year 1988-1989**

1. To make available to organizations, agencies, and persons information regarding various programs through the newsletter, presentations, etc.

2. To initiate legislation clarifying that persons with head injury are eligible for programs funded with county mill tax funds.

Progress in Meeting FY'88-89 Objectives: The council routinely provides such information via the newsletter, conferences, presentations, etc. The council initiated legislation to clarify that persons with head injury are eligible for programs receiving county mill tax funds for persons with handicaps. The bill did not pass.

Second- and Third-Year Objectives **Fiscal Years 1989-1990**

1. To sponsor workshop on funding resources, especially on HUD and Section 8 housing subsidy.

2. To meet with the state Disability Determination office and the Division of Family Services offices to discuss disability due to head injury.

About the Missouri Head Injury Advisory Council

The Missouri Head Injury Advisory Council is to be comprised of twenty-five members of which twenty-one are appointed by the Governor with advice and consent of the Missouri Senate. The twenty-one members are to represent consumers, families with a member with a head injury, professionals, proprietary schools, private industry, health industry and state agencies which administer programs regarding education, mental health, health, Medicaid, insurance, and public safety. Four members represent the Missouri General Assembly of which two members are state representatives and are appointed by the Speaker of the House of Representatives for the remainder of their terms and two members are state senators appointed by the Senate President Pro-Tempore for the remainder of their terms.

The council members elect a chairman and vice chairman for a term of one year in accordance with the bylaws.

About the Members

Judith A. Ferguson, Kimberling City, is chairman of the Missouri Head Injury Advisory Council. She replaced David B. Collins who resigned mid year after serving as vice chairman of the council. She is the founder of the Missouri Head Injury Association and is past vice president of State Association Affairs of the National Head Injury Foundation. She is a family member representative on the council having a son who suffered a head injury in 1978.

Representative Sheila Lumpe, University City, is vice chairman of the council. She served as a member of the Joint Interim Committee on Head Injury during the summer of 1984. During the 1986 legislative session, she sponsored legislation which created the head and spinal cord injury registry and established the Missouri Head Injury Advisory Council. She served as vice chairman of the House Committee on Critical Decisions and of the House Elementary and Secondary Education Committee and as a member of the House Ways and Means Committee and Budget Committee..

John F. Allan, Ed.D., Jefferson City, is the Assistant Commissioner (head) of the Division of Special Education, Department of Elementary and Secondary Education. In addition to assisting local school districts with the provision of services to handicapped children, the division is responsible for the state schools for the severely handicapped, state school for the blind, state school for the deaf, and administering the sheltered workshop subsidy Dr. Allan is a member of the American Educational Research Association and has served as a consultant for the National Center for Educational Statistics.

Michael H. Brooke, M.D., St. Louis, is Medical Director of the Irene Walter Johnson Institute of Rehabilitation, Washington University School of Medicine, and Professor of Neurology and Professor of Preventative Medicine, Washington University. He belongs to the American Neurological Association and American Academy of Neurology (Fellow). Dr. Brooke serves as the director of the Jerry Lewis Neuromuscular Research Center, Washington University School of Medicine and as a member of the Editorial Board for *Muscle & Nerve.*

Caroline A. Castillo, Kansas City, is employed at Psychiatric Centers of America. She received a Bachelor of Arts in Education in psychology in 1985 and is pursuing a Master of Arts in counseling psychology. She received a closed head injury in 1980.

Donald M. Claycomb, Ph.D., Jefferson City, is the Executive Director of the State Council on Vocational Education. He is a member of the Committee on Liaison to the National Councils on Vocational Education, National Association of State Councils on Vocational Education.

David B. Collins, Springfield, served as chairman til mid-year when he resigned to accept a job out of state. He was the vice chairman of the council from 1985 to 1987 when he was elected to serve as chairman. Until his resignation, he was employed as an Independent Living Specialist at Southwest Center for Independent Living. From December 1975 to December 1976, he was hospitalized as the result of an automobile accident. He is a member of the National Head Injury Foundation Board of Directors and is co-chairman of the Foundation's Survivors' Task Force.

Senator Edwin L. Dirck, St. Ann, served as the first chairman of the council and served form 1985 to 1987. During the summer of 1984, he chaired a Joint Interim Committee on Head Injury which held a series of statewide public hearings. Following the hearings, he introduced and passed the mandatory seat belt law. He also sponsored and passed the legislation establishing and regulating trauma centers. He served as chairman of the Senate Budget Control Committee, and as vice chairman of the Senate Aging and Mental Health Committee and the Legislative Research Committee. He also was a member of the Senate Insurance Committee and the Ways and Means Committee.

Ben H. Ernst, St. Louis, is the Director of the Rankin Technical Institute. He is past president of the Missouri Association of Private Career Schools and past president of the American Technical Educational Association. He serves as the Regional Representative of the American Technical Association; member of the American Vocational Association and is Financial Secretary to the Board of Trustees of Rankin Technical Institute.

R. Dale Findlay, Jefferson City, is the director of the Missouri Safety Council. He is past vice president of the Association of the Association of Safety Council Executives and is serving on the Governor's DWI Advisory Council. He is also a member of the Missouri Advisory Council on Alcohol and Drug Abuse.

Robert G. Frank, Ph.D, Columbia, is Associate Professor and Vice Chairman, Department of Physical Medicine and Rehabilitation, School of Medicine, University Hospital and Clinics, University of Missouri. Dr. Frank is a member of the Mid-Missouri Psychology Consortium Coordinating Committee.

Donald L. Gann, Ed.D., Assistant Commissioner (head) of the Division of Vocational Rehabilitation, Department of Elementary and Secondary Education. He is a member of the National Rehabilitation Association and the Council of State Administrators of Vocational Rehabilitation. He represented the Department of Elementary and Secondary Education on the Joint Interim Committee on Head Injury.

Charles H. Goforth, Springfield, is President and Administrator of UpJohn Health Care Services serving sixteen counties in Southwest Missouri. He is a member of the Missouri Advisory Council for Home Health Care.

L. Dennis Humphrey, Ed.D., Springfield, is a professor in the Department of Biomedical Sciences, Southwest Missouri State University. He is secretary of the Board of Directors, Springfield Coalition for Disability Rights. He is also a member of the Handicapped Advisory Committee, Mayor's Commission on Human Rights; of the Advisory Council of the Wolfner Memorial Library; and past member of the Missouri Governor's Committee on Employment of the Handicapped.

Gerald J. Kampeter, Jefferson City, is the parent of a daughter with a head injury. He has worked for the Missouri Highway and Transportation Commission for over 35 years. He is active in the Highway and Transportation Employees Association and the Travelers Protective Association of America.

Nancy Koenig, Florissant, is the parent of a son who suffered a head injury. She has served as president of the St. Louis Bi-State Chapter of the Missouri Head Injury Association and as vice president of Operation of the Association. She is a retired elementary school music teacher.

Jane Y. Kruse, Jefferson City, is the director of the Division of Medical Services, Department of Social Services. The division has responsibility for administration of the state Title (Medicaid) program. She is an attorney and a member of the Missouri Bar, Missouri Health Coordinating Council and the Alzheimer's Disease Task Force.

Donald E. McGowan, Wentzville, is safety director, BOC Group-General Motors Corporation, Wentzville Assembly Center. He is chairman of the Board of Directors of the Safety Council of Greater St. Louis and is past president of the board. He also served as a member of the Board of Directors of the Missouri Safety Council from 1980 to 1984.

Representative Marvin E. Proffer, Jackson, co-chaired the Joint Interim Committee on Head Injury. He is chairman of the House Budget Committee and the Legislative Research Committee and a member of the House Agriculture, Miscellaneous Resolutions, and Ways and Means Committees. He co-sponsored the legislation establishing the head and spinal cord injury registry and the Missouri Head Injury Advisory Council. He also sponsored legislation during the 1988 session which contained a provision for repealing the sunset provision of the seat belt law.

Thomas M. Sullivan, Jefferson City, is deputy director of the Department of Economic Development. He previously served as the director of the Missouri Senate Research and as the director of the Missouri Senate Appropriations Staff.

Nathan B. Walker, Jefferson City, is the director of the Division of Highway Safety, Department of Public Safety. He serves as Missouri's Governor's Representative to Highway Safety and is a member of the Governor's Council on DWI. He served two terms as state representative from 1980 to 1984. In 1982, he was elected as the Minority Whip of the House of Representatives.

Senator Harry Wiggins, Kansas City, served as a member of the Joint Interim Committee on Head injury in 1984. He chaired the Senate Ways and Means Committee and served as vice chairman of the Senate Judiciary and Public Health and Welfare Committees. He served also on the Senate Appropriations Committee, Interstate Cooperation and Rules, Joint Rules & Resolutions Committees. He handled the house bill in the Senate which created the head and spinal cord injury registry. He was the sponsor of the senate version.

Lorna M. Wilson, R.N., C., MSPH, Jefferson City, is the director of the Division of Local Health and Institutional Services, Department of Health. The division operates the Missouri Rehabilitation Center which has a head injury unit. She is a member of the Missouri Nurses Association, American Nurses Association, Missouri Public Health Association and the Task Force for Local Health for State Board of Health.

About the Staff

Susan L. Vaughn, M.Ed, Jefferson City, is the director of the Missouri Head Injury Advisory Council. She has over ten years of experience in state government and in the field of disabilities. She has previously been employed as a speech therapist at B.W. Sheperd State School for the Severely Handicapped, operated by the Missouri Department of Elementary and Secondary Education, as a regional coordinator of the Region IX Council on Developmental Disabilities, and by the Department of Mental Health in Jefferson City. She represented the Department of Mental Health on the Joint Interim Committee on Head Injury.

Lois M. Lorenz, Jefferson City, is the secretary for the head injury program. She has worked in state government of over seven years having worked for the Department of Mental Health both in the Division of Alcohol and Drug Abuse and for the department director's office. Prior to the department, she worked for the Office of Administration, Division of Personnel.